

Caregiver Framework  
for Seniors  
Pilot Project

2011- 2012

**Mid-term Report – Phase 1**  
**January 27, 2012**



## I. Background

The Toronto Central LHIN's *2011-14 Strategic Plan* has a primary goal of ensuring high-quality care oriented around people and communities, a goal which is closely aligned with the Ministry's *Excellent Care for All* legislation. In line with these initiatives, this demonstration project was initiated to help at-risk individuals who are the primary caregivers of elderly care recipients living at home. The Caregiver Framework for Seniors Pilot Project advances TC LHIN's *Value and Affordability* priority by identifying and addressing caregiver needs *as defined by them*.

TC LHIN stakeholder engagement has shown that most frail seniors prefer to age at home, cared for by family members able to call on appropriate community supports when and if needed. Resiliency is of critical importance in familial home care because the caregiving journey can be long and onerous, causing some caregivers to become overly stressed and unable to continue in their difficult caregiving role. From a system perspective, a major benefit to increasing caregiver resiliency is that for the care recipient, the quality of care may be improved, inappropriate visits to ER may be reduced, ALC transitions back home may occur sooner, and placement in long term care may be significantly delayed.

## II. Pilot Project Goals

Phase 1 of the Caregiver Framework for Seniors Pilot Project started in June 2011 to:

1. Develop a framework to increase the resiliency of caregivers of frail seniors living at home. The framework was intended to meet the needs of caregivers, as defined by the caregivers themselves, through individualized, supported, self-directed care plans.
2. Recruit 150 caregivers at risk or on the cusp of being at risk because of their caregiving burden (measured by a reliable screening method such as the RAI-HC or Caregiving Distress Scale).
3. Through their specially-trained care coordinator working in close consultation with each caregiver, identify factors that contribute to each caregiver's distress, and develop an individualized care plan.
4. Implement the individualized care plan (with operational support from the project if required) to relieve distress, mitigate risk and increase the resiliency of the caregiver.

## III. Project Leadership

A Core Group was created to develop the framework, liaise with project partners, and oversee the implementation and evaluation of the demonstration pilot.

- Françoise Hébert, CEO, Alzheimer Society of Toronto, as overall *Project Lead*
- Jamie Arthur, Client Services Manager Seniors Enhanced Care Program of the TC CCAC, as *Care Coordinator Team Lead*
- Carol Kushner, health policy consultant, as *Framework Lead*
- Frances Morton, health policy researcher and doctoral student in dementia care, as *Orientation Group Lead*
- Marija Padjen, Chief Program Officer, Alzheimer Society of Toronto
- Stephanie Smit, Consultant, Toronto Central LHIN
- Natalie Warrick, as *Project Coordinator*

## IV. Statistical Summary (Phase 1 mid-term to January 13, 2011)

Caregiver – total recruited to date	109
Caregiver – average age	69
Caregiver – range of age	Youngest 39 Oldest 95
Caregiver – sex	Female 76 % Male 24 %
Caregiver relationship to care recipient (n=57)	Spouse 60 % Child 38 %
Caregiver – financial need (as observed by care coordinators)	97 %
Total funds spent to date to implement care plans	\$ 162,295
Average spending per caregiver (n = 104)	\$ 1,560
Caregiver satisfaction (n=57)	8.8 out of 10

### Services selected in care plans

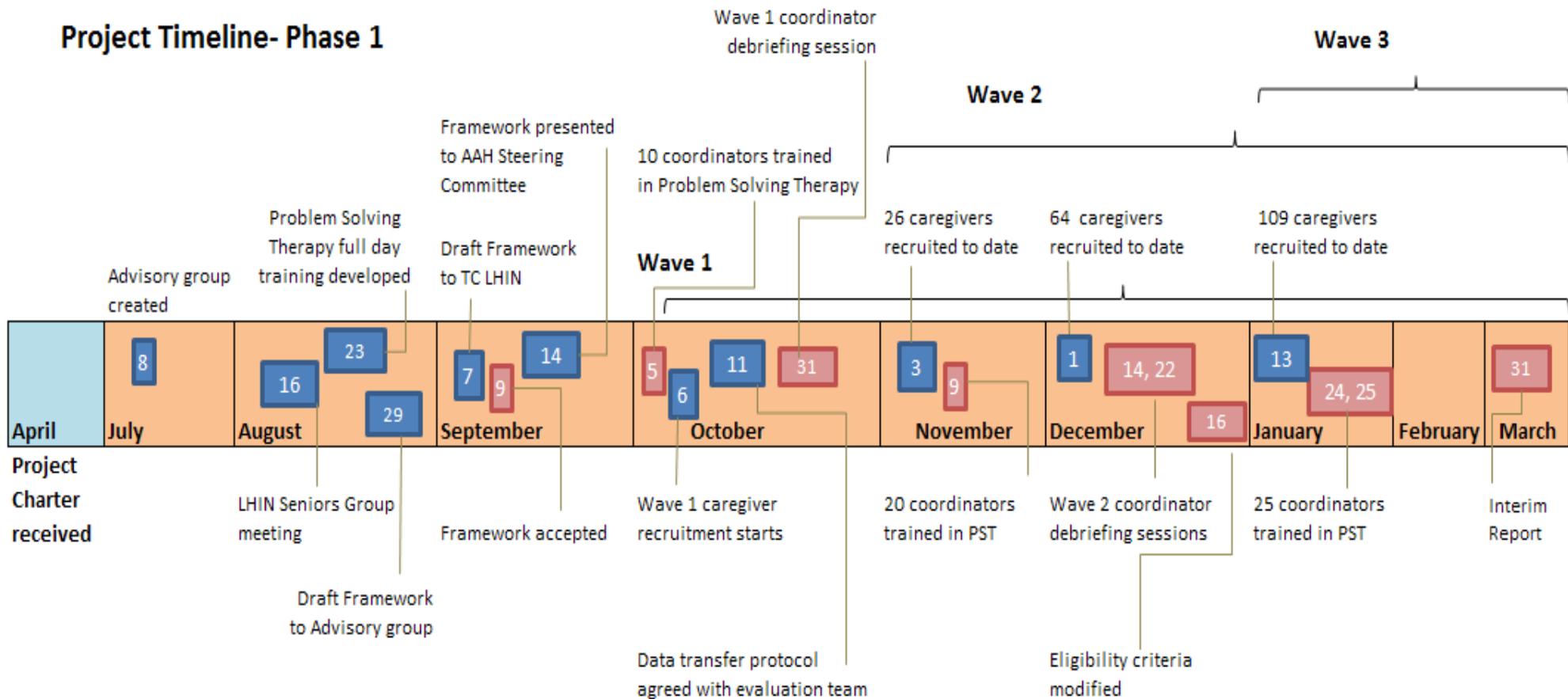
Service	Percentage			Amount	
	Men (24%) (n=26)	Women (76%) (n=78)	Total Caregivers (n=104)	% of funds Spent	Total Spent
Informal care (relative, friend, neighbour, etc.)	38%	29%	31%	26%	\$42,860
Personal support worker	15%	22%	20%	15%	\$24,820
Home help (MOWs, cleaning services)	4%	11%	9%	3%	\$3,998
Short-stay respite	0%	6%	5%	3%	\$4,156
Adult day program	8%	5%	6%	3%	\$4,176
Health care supplies	31%	27%	28%	10%	\$16,139
Transportation	15%	18%	17%	5%	\$7,234
Social activity / self-care	12%	24%	21%	6%	\$10,187
Bill payment	15%	14%	14%	10%	\$16,904
Physiotherapy	8%	17%	15%	6%	\$10,257
Equipment	15%	18%	17%	13%	\$21,064
Other	0%	1%	1%	0%	\$500

Self-reported ethnic group	Caregivers
White	54%
Asian / Southeast Asian	8%
South Asian	8%
Other/Declined to state	8%
Black	6%
Italian	6%
Portuguese	5%
Latin American	3%
Russian / Ukrainian	2%
Aboriginal	2%
West Asian / Arab	0%

Language	Caregivers
English	65%
Italian	8%
Portuguese	6%
Russian / Ukrainian	5%
Cantonese / Mandarin	3%
Spanish	3%
Greek	2%
Croatian	1%
Hindu	1%
Polish	1%
Tagalog	1%
Vietnamese	1%

\*Columns/rows do not total 100% as care plans may include multiple items.

### Project Timeline- Phase 1



**Legend**

- Training, expert panels and reports
- Meetings and caregiver recruitment

## V. Early Findings

### Framework strategies

- The literature regarding caregiver supports has been inconclusive to date, with a paucity of evidence on the effectiveness of caregiver interventions and their impact on the health system. This project holds great promise for success in identifying at-risk caregivers and eliciting their own insights in developing an innovative and flexible mix of supports that can help them in their difficult caregiving role.
- Simpler and more reliable assessment tools are needed to identify caregivers in distress. To address this need, Dr. Sadavoy has modified a Caregiving Distress Scale Tool for use in Phase 2.
- Care coordinators needed special training on the practical aspects of *Problem-Solving Therapy*, because this project requires a paradigm-shifting conversation with the caregiver that is substantively different from the care coordinator's normal practice.
- Face-to-face dialogue between the specially-trained care coordinator and the caregiver is essential to identify and prioritize stressors, agree on achievable goals and develop an individualized care plan to improve the situation.
- Administrative/operational support for implementing the individual care plan is useful to save care coordinator time, and to enable the aggregation of commonly requested services to achieve efficiency savings.

### *Problem Solving Therapy* training for care coordinators

- The goal of *Problem Solving Therapy* training for care coordinators is to teach them to engage with caregivers in a focused way to identify specific problems, agree on achievable goals and develop practicable interventions tailored to achieve those goals.
- Care coordinators normally focus on the client rather than the caregiver, and are limited in both the type and duration of services that the CCAC can provide to the client. In this project, the focus is on the caregiver: the care coordinator must exercise considerable judgment and has an unusual amount of financial and service flexibility in negotiating the individualized care plan with the caregiver.
- To date, 30 care coordinators from the Toronto Central CCAC have been trained in *Problem Solving Therapy* by Dr. Joel Sadavoy and Dr. Virginia Wesson of the Reitman Centre for Alzheimer Support and Training at Mount Sinai Hospital, assisted by mental health clinicians Caitlin Agla, Valeria Grofman and K.C. Chan. All care coordinators receive this training before taking part in the pilot project.



### Early feedback from care coordinators

Care coordinators met in small groups about four weeks after the project start to share their experiences and provide feedback for mid-term course corrections. Coordinator debriefing sessions were facilitated by Dr. Paul Williams and his evaluation team (Jillian Watkins, Allie Peckham and David Rudoler) of the Institute for Health Policy, Management and Evaluation at the University of Toronto.

- Care coordinators have asked for administrative advice regarding practical examples of care plans, particularly regarding funding averages and spending limits for care plans. The project coordinator has been available via email and telephone to respond to these requests.
- Care coordinators have recommended useful and innovative care plans. Project leaders have not second-guessed the care plans agreed by the care coordinator in consultation with the caregiver – this project places great trust in the care coordinators.
- Care coordinators appreciate access to a hierarchy of advisors to consult if they have questions about individual cases.
- Care coordinators report that the flexibility and minimal paperwork requirements of this project allow them to spend maximum time with their client, resulting in more thoughtful and creative individualized care plans.
- Funds requested in the earlier care plans averaged \$1,080 per caregiver. As the care coordinators became more comfortable with the project, spending increased to \$1,560 per caregiver, close to the project's estimated average of \$1,500 per caregiver.

Coordinators debriefings revealed that care coordinators are positive about the impact of the pilot project and appreciate the flexibility it gives them in providing caregivers with the supports they need to carry on their caregiving activities. Care coordinators felt strongly that caregiver burden is multi-factorial and that helping caregivers inevitably helps their client. The debriefing sessions highlighted a range of early concerns, including managing caregiver expectations around an unconstrained basket of services, the ability of the project to isolate and measure outcomes directly affected by the program, and the most effective and efficient means of implementing care plans and transferring funds to caregivers or service providers. To address these and other concerns that might arise as the project unfolds, the project coordinator now attends monthly coordinator meetings.

A detailed report of the care coordinator debriefings is attached as **Appendix A**. Based on care coordinator feedback, project attention focused on the following:

1. Initial caregiver definitions and eligibility criteria in the September 2011 Framework, seemed not to be expansive enough. These were reviewed and changed by the Core Group in December 2011.
  - *Adult caregivers of any age who provide care to seniors in TC-LHIN should be eligible to participate.*
  - *Caregivers may not live with the person they care for, so caregivers living outside of TC LHIN should be eligible if the person they care for lives in TC-LHIN.*

2. Though not specified as selection criteria for this project, care coordinators identified considerations and characteristics that they had looked for when selecting caregivers:

- *experiencing cultural barriers—in particular language barriers*
- *low income*
- *limited family support*
- *recently experienced an acute episode*
- *holding paid employment, and loss of paid employment as a consequence of new caregiving burden*
- *struggling with their own mental health problems*
- *in frail health*
- *in the caregiving role longer than 6 months*
- *care recipient at risk for entering long-term care or hospital*

3. Care coordinators were asked how they would know if this pilot project was successful. They surmised that under certain circumstances, the intervention is likely to have positive effects, including outcomes for:

- Informal caregivers: maintained and/or improved social, emotional and physical well-being (e.g. caregiver able to sleep through the night). *The Caregiving Distress Scale will be used as an objective measure.*
- Care recipients: able to stay in their current living environment with additional supports provided by the project. *We will track the number of care recipients who go in to long-term care.*
- Care coordinators: By engaging in an in depth conversation with the caregiver and offering a flexible range of services to address individual situations, care coordinators gain greater professional satisfaction. Conversely, this approach takes more time and therefore increases their workload. *We will continue to engage care coordinators at debriefing sessions to gather feedback regarding their satisfaction and workload.*
- Health care system: this project has the potential to reduce the number of crisis applications, resulting in cost savings to the system on the whole. *We will work with project partners to track crisis placements.*

## VI. Progress Toward Project Goals



**Caregivers are being heard** and they feel valued for the contributions that they make in caring for a loved one at home. **Care coordinators are able to discuss individual needs, build trust, and give caregivers a direct voice in developing a care plan tailored to suit their unique situation.** One care coordinator said, “I have the client’s (care recipient) name on my sheet, but I care and consider the whole household.” This directly supports a person-centred care approach and is in alignment with the TC LHIN *Value and Affordability initiative*.

### Next Steps

1. By March 31, 2012 meet the Phase 1 goal of 150 caregivers recruited for the Pilot Project. At the same time, add the Phase 2 recruitment goal of 125 continuing and 150 new caregivers, for a total of 300 caregivers eventually taking part in both phases of the project.
2. Invite the Mount Sinai Reitman Centre, the Alzheimer Society of Toronto, COPA, Mid-Toronto Community Services, St. Stephen’s Community House and St. Christopher House to join the project by recruiting 20 at risk caregivers each from their client roster. These agencies were chosen because of the geographic region they serve and because of they are likely to encounter at risk caregivers in the course of their work.
3. Ensure that all care coordinators (from CCAC and other organizations) taking part in the project receive Problem Solving Therapy training before they start recruiting caregivers.
4. Incorporate feedback from coordinator debriefing sessions into the training program to improve the care coordinators’ sense of ease with the open-ended nature and flexibility of the project, and to give them the confidence they need to respond creatively and to take risks within approved limits.
5. Continue to support care coordinators in implementing the care plans that they develop in consultation with the caregiver.
6. Carefully monitor project expenses, and take reasonable steps to ensure that funds are used appropriately.
7. Contract with Dr. Joel Sadavoy’s team at the Reitman Centre to conduct face-to-face interviews with caregivers who have taken part in this project, to gauge their subjective assessment of the project in reducing stress and increasing their resiliency.
8. Continue to conduct coordinator debriefing sessions with care coordinators to incorporate new learnings into the project to the end of Phase 2.
9. Keep Toronto Central LHIN fully informed on agreed project milestones.
10. Prepare report at the end of Phase 1 (March 31, 2012) and Phase 2 to describe the processes and findings of the project to share all learnings. At the end of the project, share observations/findings on if and how the project was able to reduce caregiver stress, increase resiliency in caring for a senior, and provide recommendations as to whether such approaches can be incorporated into standard best practices going forward.

## VII. Case Vignettes \*

\* For reasons of privacy, all names have been changed. Photos are representative only, taken from stock sources.

### 1. ER aversion



A home visit was arranged with Anh (age 81), caring for her husband at home. Their daughter and an interpreter were present at the visit. The husband is waiting for a crisis LTC bed. Meanwhile, Anh is

exhausted because her husband wants her around all the time and is very demanding. She is at the end of her rope and must get away to rest (she was packing her bags at the time of home visit). Her husband would have been without care, and the daughter had taken the afternoon off work to drop her dad off at ER.

Goal: For Anh to get the break she needs, and for her husband to be cared for at home to prevent inappropriate drop-off at ER.

Care Plan: The daughter was able to take a short unpaid leave from her job to care for her father while her mother visited a friend for eight days. The project paid for the daughter to care for her father at his home.

Benefit: Inappropriate visit to ER was avoided. Husband may be taken off crisis placement list if similar respite can be arranged in future.

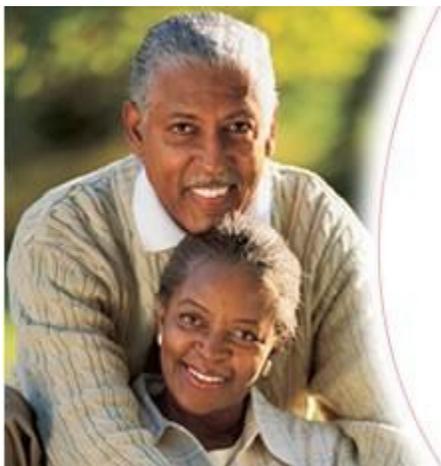
### 2. Crisis application aversion

Ofelia at 39 was in the final months of a high risk pregnancy for her first child. With a newborn baby she would not be able to care for her mother who had suffered a stroke causing cognitive decline. Without additional support Ofelia would have to request a crisis placement for her mother.

Goal: Ensure Ofelia has the help she needs following the birth of her baby.

Care Plan: Provide 17 hours of additional PSW support for up to six weeks after Ofelia gives birth, to a maximum of \$1500.

Benefit: This project provided short-term funds that obviated the need for the premature placement of Ofelia's mother in long term care. If all goes well with the new baby, placement may be delayed significantly.



3. **Potentially reduced ALC**

Leroy (50) provides total care for his mother who has experienced several hospital readmissions. His mother recently came back home from an acute stay in hospital, after presenting in ER with chronic infections believed to have started as a dental issue.

**Goal:** Dental work to prevent recurring tooth infections.

**Benefit:** His mother receives needed dental care, the system benefits from reduced ER visits and days in ALC. Leroy is pleased that his mother is no longer in pain.

**Care Plan:** Provide funding for Leroy to pay for treatment of the dental problem, infections will become less frequent, theoretically reducing the need for ER and ALC. Leroy was relieved of having to make frequent visits to the ER which had been causing him tremendous stress.



4. **Reduced caregiver stress**

Anjay (67) cares for his mother who has advanced Alzheimer's and who walks with an unsteady gait. He provides around the clock care to his mother. Anjay's sister

recently began bringing a tablet PC with her on her visits to see their mother. Their mother was amused by the device which kept her occupied and prevented her from pacing, which was very stressful for Anjay.

**Goal:** Be able to leave the room and feel content knowing that his mother is occupied with an environmentally enriching game.

**Care Plan:** Anjay purchased a tablet PC for his mother to occupy her time. He will also see a counselor to learn how to deal with her responsive behaviours.

**Benefit:** Anjay feels less burdened and distressed as he no longer has to watch over her mother while she paces out of fear that she may fall, or injure herself in the process. His mother may demonstrate higher cognitive performance, and/or demonstrate fewer responsive behaviours.

5. **Reduced physical strain**

Daniela (76) cares for her husband Gerald. She struggles to perform the physical tasks associated with caregiving.

**Goal:** To prevent and/or reduce her husband's bed sores, and enable her to transfer her husband safely and frequently from his bed to his chair without hurting her back.

**Care Plan:** Daniela opted to purchase a hooyer lift and incontinence supplies (pads and diaper rash ointment). She will also hire a private attendant who speaks Ukrainian to provide care for her husband four hours weekly for three months at \$15 per hour, allowing Daniela needed respite to visit her brother.

**Benefit:** Relieve the physical strain of caregiving. Reduce amount of time spent doing laundry preventing caregiver burn out, and allowing for Daniela to have some time to engage in fostering her own mental, physical and emotional health.

## 6. Improved caregiver health and wellness

Jing Wah is 57. She lives with her mother-in-law and uses a hooyer lift to move her to the toilet and the bed. Jing Wah is experiencing increasing back pain as a result of the physical demands of her caregiving role. She was previously receiving physiotherapy as an employee benefit. No longer employed, she can no longer afford physiotherapy. There is demonstrable financial need.

Goal: At the beginning of her meeting with the specially-trained care coordinator, Jing Wah assumed the focus was to help her mother-in-law. The coordinator relied on problem solving therapy (PST) to dig deeper into

the source of Jing Wah's anxiety, learning for the first time that an automobile accident had caused her back pain.

Care Plan: Jing Wah requested physiotherapy and a \$200 gift card to Walmart for the purchase of incontinence supplies to reduce the number of transfers to toilet.

Benefit: Jing Wah experiences reduced back pain, increased physical strength and improved flexibility. Jing Wah was elated to hear of a program meant specifically to address her personal needs. She cried with relief that someone was listening, and valuing her contribution.

## VIII. Testimonials (representative sample, unedited)

Caregivers completed a short questionnaire sent to them by mail which asked their opinion on whether the caregiver project is helping to meet their needs as caregivers. The majority of responses have been positive (9s and 10s on a scale of 10), only one caregiver gave less than 5.



Satisfaction Scale

"The Caregiver Project for Seniors is excellent assistance for us. It will help other families who are struggling with their loved ones who are very sick. Please continue this help for caregivers so that the caregivers will have some relief and are able to take care of their health to enable them to take care of their loved ones." **10 out of 10**

"I know that if I have any questions or concerns I can contact them. Something that has bothered me is when I asked for help before, Mom got worse, like having a senior come and visit her just to talk to her as a friend over a cup, there wasn't anything there for her and that bothered me. There was either a cost or there was nothing in her area. I would like to thank the caregiver program for the help, it is much appreciated." **10 out of 10**

"A extra day to clean up cellar and garage. We are afraid of falling doing these chores. We can't do them." **10 out of 10**

“Financial help received toward paying for private care and supplies, has been beneficial but does not cover expenses associated with providing a quality of care at home for loved ones. I feel that keeping my mother with me is the best thing for her. “	10 out of 10
“It will help a lot because everything helps. Every bit helps, more hours would be helpful and for a longer period of time.”	10 out of 10
“I think it is an excellent idea. Provides stimulation for my brother and gives me a break. I get very tired and stressed often. I do not want to burn out.”	10 out of 10
“The taxi vouchers helped a lot. I had fallen last month (3 times).”	10 out of 10
“CCAC caregiver support program sponsors my husband going to adult day program twice a week. This will provide good relief for me so that I can have a break. Then I will be able to manage taking care of my husband at night.”	10 out of 10
“My needs are met with the 3 days a week adult care and CCAC 14 hours/week- as I have been responsible 24/7 and last had dinner with my husband in August. This additional time for me has made a significant change in my attitude. I can breathe again.”	9 out of 10
“I did not know how badly I needed help until CCAC/CBI started sending PSWs to help. A little break.”	8 out of 10
“The project will help in many ways to relieve the stress... at the present time, my mind is confused and stressed out.”	7 out of 10
“Caregiver project is a unique, helpful and very encouraging for the primary caregiver to have a relief, rest and re-energize to help take care of the person who needed the help most. “	7 out of 10
“The help is a great benefit as I also have health issues.”	6 out of 10
“More hour is the only thing that I require.”	6 out of 10
“It will help to cover some of my expenses and medical equipment expenses, provide more financial.”	6 out of 10
“More time to spend off.”	3 out of 10

**Appendix A: Caregiver Framework – Formative Evaluation – Preliminary 2012**

Please see attached PDF.