

Caregiver Framework
for Seniors
Demonstration Project

2012

Interim Evaluation

June 30, 2012

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Executive Summary

Caregiver Framework for Seniors Demonstration Project

Interim Evaluation – June 30, 2012

Policy Goals: This project is intended to increase the resiliency of at-risk caregivers caring at home for a senior family member with high care needs. Caregiver resiliency is critically important in home care because the caregiving journey can be emotionally, physically and financially onerous over several years, causing some caregivers to become so stressed or ill that they are unable to continue in their difficult caregiving role. The project pursues a valid public policy objective because of the important role that family caregivers play in preventing avoidable ED visits, speeding transitions from ALC to home, and delaying long term placement. If increased caregiver resiliency can achieve these goals, even modestly, then savings to the health care system could be significant.

An evaluation strategy was embedded in the project from the outset, drawing on qualitative and quantitative data to measure the impact of the project on the caregivers and on the system of care.

Project Approach: This project offered an innovative approach to increasing the resiliency of at-risk caregivers. Care coordinators were trained in Problem Solving Therapy by geriatric psychiatrist Dr. Joel Sadavoy and his clinical team at Mt. Sinai Hospital. The coordinators then recruited from their normal caseload up to five caregivers who had been objectively identified as being 'at risk' or 'on the cusp of being at risk' of burnout. The coordinators engaged in a problem-solving dialogue with the caregivers, exploring the causes of their distress, and in collaboration with them, developing a flexible care plan aimed at relieving their distress, with financial and implementation support available from the project office as required.

The project proceeded in two phases. Starting in October 2011, Phase 1 recruited 150 at-risk caregivers from the TC-CCAC SEC program. Phase 2, starting in January 2012, increased the recruitment target to 300 caregivers and invited seven other community service agencies to participate. As of June 20, 2012, some 281 caregivers have been recruited and their care plans activated. Another 26 caregivers are on a waitlist for care plan activation.

Caregivers have an average age of 66, the oldest being 95 years old. Some 77% are female, most are the spouses of the care recipient, and all have an observed financial need. They are mainly white (54%) and English speaking (71%), but a significant number have diverse ethnic, cultural or linguistic backgrounds.

Care plans are uniquely tailored to the individual circumstance of the caregivers, who were asked to think creatively about the situations they found most stressful in their caregiving role, and how the principal causes of stress could be mitigated.

The most requested interventions were for paid informal respite care from relatives, friends and neighbours (31%), followed by health care supplies (25%), agency-provided personal support workers (22%) and funds for social activities or self-care (20%). Most interventions were congruent with project expectations, within suggested budgetary guidelines and in keeping with the goals of reducing caregiver stress. There were approved and activated within one or two weeks.

Costs of care plan interventions had been budgeted at \$1,500 per care plan or a total expenditure of \$450,000 for 300 caregivers. To date the average cost has been \$1,462 per care plan, totalling \$410,919.

Project Findings: Analysis is incomplete and findings are preliminary. Satisfaction ratings by 156 caregivers to date are 8.8 out of 10. It is obvious that caregivers appreciate the project, but because of the complexity of their situations, it is not yet possible to objectively determine if the project interventions increased their resiliency and achieved the hoped-for public policy goals. Virtually all caregivers are positive about the project's impact on them, and hopeful that it will continue.

Care coordinators unanimously agreed that the project has a positive impact on caregivers, who feel more knowledgeable about services that can help them, more empowered and more appreciated in their difficult caregiving role. Concerning their own critical role in the project, care coordinators admit that while the problem-solving sessions with caregivers increase their workload, they feel that these conversations are important and beneficial. They appreciate being able to provide almost immediate support to the caregivers because of the expediency and efficiency of the project office. And finally, the care coordinators appreciate the trust that was placed in them in this project, and the discretion and professional judgement that they were able to apply in their paradigm-shifting discussions with the caregivers, discussions that differed so significantly from their normal practice.

This project is particularly noteworthy because it does not offer fixed services or benefits, but rather encourages thinking 'outside the basket' and establishes a supported self-management platform for negotiating support packages tailored to the individual circumstances of each caregiver. The similar *Cash and Counselling* project in the U.S. found that caregivers who are able to exert greater control over their care are significantly more satisfied with and worry less about the overall care they receive, and are less likely to report emotional, physical or financial strain than caregivers who are limited to a specific basket of services.

Interim Recommendations:

1. That care coordinators and caregivers be connected with additional resources in the community, for more in-depth counselling, support and education, addressing an unmet need clearly identified in this project.
2. That TC-LHIN, TC-CCAC and the Alzheimer society of Toronto initiate discussions to take the best lessons learned in this project, and embed them in the Seniors Enhanced Care (SEC) program at TC-CCAC so that they can be applied to the entire population of at-risk caregivers of SEC clients.

1. Why this Evaluation Report?

The *Caregiver Framework for Seniors* demonstration project was initiated in June 2011, with an overarching goal to increase the resiliency of at-risk caregivers caring at home for a senior family member with high care needs.

Research has shown that most frail seniors prefer to age at home, cared for by family members and supported by community services if and when needed. The resiliency of family caregivers is of critical importance in home care because the caregiving journey can be emotionally, physically and financially onerous over several years, causing some caregivers to become so stressed or ill that they are unable to continue in their difficult caregiving role.

Increasing the resiliency of family caregivers is a valid policy objective because of the important role that caregivers can play in preventing avoidable ER visits, enabling smooth ALC transitions back home, and delaying long-term care placement. If increased caregiver resiliency can contribute to these goals even modestly, then cost savings for the health care system could be significant.

This project offered an innovative approach to increasing caregiver resiliency. Care coordinators from the Toronto Central CCAC and selected other agencies received Problem Solving Therapy training, in which they learned to engage caregivers in identifying their problems in a highly focused way. Care coordinators then identified up to five caregivers from their normal caseload, who had been objectively identified as being 'at risk' or 'on the cusp of being at risk' of burnout.

The coordinators engaged in a problem solving dialogue with each caregiver, explored the principal causes of their distress, and developed in collaboration with them an individualized flexible care plan aimed at relieving their distress, with financial and implementation support available on request from the project coordinator. Through the first eight months of the project, which caregivers clearly understood would be of limited duration, qualitative and quantitative data were collected to measure the impact of the project intervention on the caregivers, and on the system of care.

Eight months from project launch is insufficient time to support a full assessment of the impact of the project. An *Interim Evaluation Report* conducted by the University of Toronto's Balance of Care Research Group is thorough and important and constitutes an integral part of this evaluation, but is based on data relating to fewer than half of the caregivers recruited to date.

And yet from this and other sources, certain early conclusions can reasonably be drawn, and observations offered to assist in the decision that must soon be made about the future of this project.

2. Project Goals and Methodology

The *Caregiver Framework for Seniors* project began in June 2011. Distinct steps were to:

- Develop a theoretical framework to increase the resiliency of caregivers by reducing the stress that causes them to feel isolated, overwhelmed or depressed, and that can increase the risk that they will not be able to continue in their demanding caregiving role.
- Develop a practicable approach to apply the framework through negotiated individualized, supported, self-directed care plans.
- Develop an evaluation strategy drawing on multiple qualitative and quantitative data sources to measure the impact of the interventions on caregivers and on the system of care.
- Starting in October 2011, implement the project by training 30 TC-CCAC care coordinators in *Problem Solving Therapy*, teaching them the innovative techniques they would need in order to engage with caregivers in a way that differed significantly from their usual practice.
- Invite each trained care coordinator to select from their own client roster five or more objectively-identified at-risk caregivers, and recruit those caregivers into the project, for an initial project target of 150 at-risk caregivers.
- Explore the causes of each caregiver's distress using the problem solving therapy technique in a face-to-face conversation, working closely together to negotiate an individualized support package, at a suggested average cost of \$1,500.
- Activate the individualized support package, with efficient and timely financial and administrative support from the project coordinator.

In December 2011, TC-LHIN advised that additional funds would be made available to continue the project, so timelines were extended into 2012-2013, and a new project goal of 300 caregivers in total was set. Caregivers recruited in Phase 1 were offered the opportunity to continue in Phase 2, and seven other community support service agencies were invited take part in the project - Alzheimer Society of Toronto, Centres d'Accueil Héritage, Community Outreach Program in Addictions (COPA), Mount Sinai Reitman Centre, St. Clair West Services for Seniors, St. Stephen's Community House and St. Christopher House.

3. Project Implementation: October 2011 - June 2012

3.1 The Target Population: At-risk Caregivers

From the outset, the project targeted at-risk unpaid caregivers of frail high-need seniors living at home. In July 2011, the TC-CCAC *Seniors Enhanced Care* (SEC) program had 874 caregivers flagged as being at risk, providing a well-defined target population from which to recruit caregivers to the project: Caregivers in the SEC database had consistent RAI and other assessment data, plus an existing relationship with a care coordinator, two important considerations for a rapid project start dictated by tight timelines, and for evaluation purposes.

Selection criteria for caregivers were straightforward: The care recipient must be 65 years of age or older, or otherwise identified as a “senior”, and reside in the TC-LHIN catchment area. The caregiver must provide at least ten unpaid hours of direct care per week, but need not live with the care recipient or in the TC-LHIN.

Caregiver risk was measured via the *Resident Assessment Instrument – Home Care* (RAI-HC) or the *Resident Assessment Instrument – Community Health Assessment* (RAI-CHA), which flag a client as having a ‘caregiver in distress’ when one or more of 3 triggers are present:

- 1) the caregiver is unable to continue in this role for any reason
- 2) the caregiver is not satisfied with the support that others provide in caring for the client
- 3) the caregiver expresses distress, anger or conflict because of caring for the client.

The seven community support service agencies joining the project in February 2012 used other validated instruments to assess caregiver risk if RAI data were not available.

Caregiver characteristics (October 2011 to June 22, 2012)

| | | | | |
|---|------|--------------------|-----|-----------|
| Caregivers – recruited to date (includes 36 caregivers continuing to Phase 2) | | | | 281 |
| Caregivers – average age | | | | 66 |
| Caregivers – range of age | | Youngest | 24 | Oldest 95 |
| Caregivers – sex | | Female | 77% | Male 23 % |
| Caregivers – financial need (observed by care coordinators) | | | | 97 % |
| Self-reported ethnic group | | Language | | |
| White | 54 % | English | | 71 % |
| Other / Declined to state | 18 % | Italian | | 9 % |
| Asian / Southeast Asian | 8 % | Portuguese | | 6 % |
| Black | 7 % | Cantonese/Mandarin | | 2 % |
| South Asian | 7 % | Greek | | 2 % |
| Filipino | 3 % | Ilocano/Tagalog | | 2 % |
| Latin American | 2 % | Spanish | | 2 % |
| West Asian | 1 % | Russian/Ukrainian | | 1 % |
| Aboriginal | 1 % | Polish | | 1 % |
| | | Hindi/Gujarati | | .8 % |
| | | Vietnamese | | .8 % |
| | | Croatian | | .4 % |
| | | Farsi | | .4 % |
| | | Korean | | .4 % |

3.2 The Care Coordinators and Problem Solving Therapy

Before they can begin recruiting caregivers to the project, care coordinators receive a full-day of training in Problem Solving Therapy, developed and provided by geriatric psychiatrist Dr. Joel Sadavoy and his clinical team at Mount Sinai Hospital. Care coordinators receive special training in Problem Solving Therapy because their role in this project calls for a paradigm-shifting approach that may be substantively different from normal practice: CCAC clients are most frequently the care recipient, and thus most conversations are driven by their expressed needs, rather than the needs of their caregiver.

Care coordinators at CCAC perform a dual function in that they are brokers of care resources and also case managers. As such, they must contend with limitations in the type, duration and cost of services that can be provided to their clients.

In this project, a great amount of trust is placed in the care coordinator, who can exercise considerable discretion, creativity and professional judgment in negotiating the individualized care plan with the caregiver. They must select just a few eligible caregivers from their own client roster, meet with them to explain project goals, and obtain their informed consent to participate. Following the intake process, care coordinators engage in a problem solving dialogue with each caregiver, to identify and prioritize causes of their distress, discuss a highly flexible range of interventions, and then negotiate and agree on a practicable care plan that includes interventions tailored to the individual situation.

Care coordinators trained

| | |
|--|----|
| Phase 1 | |
| Toronto Central Community Care Access Centre | 30 |
| Phase 2 | |
| Toronto Central Community Care Access Centre | 24 |
| Alzheimer Society of Toronto | 7 |
| Community Outreach Program in the Addictions | 5 |
| Les Centres d'Accueil Héritage | 4 |
| St. Christopher House | 4 |
| St. Clair West Services for Seniors | 3 |
| St. Stephen's Community House | 3 |

The evaluation strategy for this project calls for regular debriefing sessions with care coordinators and their managers, to identify, document and continuously learn from their experiences on the front line. The Balance of Care Research Group conducts these semi-structured debriefing sessions with the care coordinators, and detailed findings can be found in their Evaluation Interim Report, which is attached.

3.3 Forms and Processes

Six forms are used in this project.

1. **Consent form**, signed by the caregiver following a scripted introduction by the care coordinator, explaining that:
 - the project is time limited
 - the caregiver can withdraw at any time without penalty to services currently provided
 - funding will cease if the care recipient no longer requires care at home
 - funding must be used as intended and agreed to in the care plan (caregivers may revise spending in care plans as needs change subject to further approval)
 - the project will maintain the highest level of privacy and confidentiality
 - the caregiver must collaborate in developing their own individualized care plan
 - the caregiver may be asked to provide receipts for items purchased
 - the caregiver will be asked to respond to one or more surveys
2. **Caregiver Assessment**, conducted by care coordinators for baseline measurement and evaluation. *Resident Assessment Instrument–Home Care* (RAI-HC) and *Resident Assessment Instrument–Community Health Assessment* (RAI-CHA) are completed as per usual case management practice. A *Caregiver Distress Scale* is used by agencies not using the RAI.
3. **Care Plan**, completed by the care coordinator utilizing the problem solving technique to describe stressors discussed with the caregiver, and the interventions agreed between them.
4. **Implementation Plan** completed by the care coordinator and the project coordinator to estimate the cost of the agreed interventions, and to assign responsibility for activation and follow-up. An interdisciplinary team advises on the appropriateness of requested equipment and safety devices.
5. **Funding Authorization** required review and sign off according to the appropriate dollar amount. The project as designed is transparent to Alzheimer Society of Toronto auditors and to TC-LHIN, our funders. Appropriate controls are in place to ensure thorough review of care plans. Funding Authorization Approval is as follows:
 - For amounts up to \$1500 - AST Senior Management
 - For amounts over \$1500 - AST Project Lead

Each client file also contains the following:

- Consent form detailing that the caregiver will use all funding provided as intended
 - Signed approval of care plan and dollar amounts approved
 - Receipts, invoices and tracking sheets (where required)
6. **Caregiver Questionnaire(s)** mailed to each caregiver directly by the project coordinator when the care plan is approved. Questionnaires are returned to the project coordinator.

3.4 The Care Plan Interventions

Caregivers were invited to think creatively about the situations they found most stressful, and worked with their care coordinator to develop a plan uniquely tailored to their individual circumstances. Normal rules about the types of services that could be funded by the CCAC were set aside, the focus placed instead on the needs of the caregivers as defined by them.

| Interventions Requested in Care Plans (n=281) | %* |
|---|------|
| Informal respite care (relative, friend, neighbour, etc.) <i>Usually paid by the hour for one or more weeks while caregiver takes a vacation, or for several hours per day or per week over a longer period of time for caregiver to enjoy personal time away from home (go to church, doctor visits, family outings, etc...)</i> | 31 % |
| Health care supplies <i>Incontinence supplies, vitamins and supplements for caregivers and/or care recipients, medications not covered under Ontario Formulary, traditional Chinese medicine.</i> | 25 % |
| Personal Support Worker <i>Preferably the same PSW provided by the CCAC, but otherwise any PSW agency.</i> | 22 % |
| Social activity / self-care <i>Caregivers purchased tickets to attend events such as cinema, theatre, ballet, or gift cards for themselves, the care recipient and their family to attend events together.</i> | 20 % |
| Equipment <i>Direct purchase of hospital bed, Hoyer lift, stair glide, bathroom commode, mattress, wheelchair, walker, etc.</i> | 19 % |
| Physiotherapy/acupuncture / gym <i>Payment for caregiver or care recipient to receive physiotherapy not covered under OHIP.</i> | 16 % |
| Bill payment <i>Payment of electricity bill, groceries, courses at university or trade college to improve job marketability, or to improve caregiving skills (i.e. PSW course).</i> | 15 % |
| Transportation <i>Taxi chits to attend medical appointments, church, adult day programs, other</i> | 15 % |
| Home help (Meals on Wheels, cleaning services) <i>De-cluttering services, bed bug pest removal, cleaning, snow removal, and home repair.</i> | 12 % |
| Adult day program <i>Fees for initiation or addition of days for care recipient, providing caregiver respite.</i> | 9 % |
| Short-stay respite in a residential facility <i>Caregivers recovering from recent surgery or who needed a short leave of absence to attend to overseas family matters opted to move their care recipient into a residential facility for a defined period of time (generally 3-4 weeks).</i> | 7 % |

*Percent column totals more than 100 because many care plans requested multiple interventions

- Most interventions were congruent with framework expectations, within suggested budgetary guidelines, and in keeping with the goals of reducing caregiver stress. These were approved and implementation proceeded apace, usually within one or two weeks.
- Intervention requests that were unusually costly or seemed questionable elicited a more thorough review. In these few cases, the project coordinator requested that the care coordinator discuss the case with their own manager, and provide fuller details to justify. There was a deliberate effort not to second-guess interventions agreed between the care coordinator and the caregiver, but in rare instances care coordinators were asked to renegotiate the requested interventions with the caregiver to reduce costs or to select more realistic interventions to achieve the same goal.
- Straightforward interventions such as additional personal support worker hours were generally arranged by the care coordinator, with invoices submitted to the project for payment. The project coordinator assumed the responsibility for such arrangements if requested by the care coordinator.
- Caregivers who preferred to arrange their own intervention were sent a cheque by mail by the project coordinator, and asked to provide receipts for large items (such as hospital beds or safety equipment), or invoice tracking sheets, in order to verify that funds had been used as intended.
- Care coordinators were asked to follow up with their caregiver approximately one month after activation of the care plan intervention, to ensure that things were proceeding as expected, and to assist in addressing unexpected difficulties. Because of work load, some care coordinators asked the project coordinator to assume this follow-up task.
- It was anticipated that a small number of caregivers receiving cheques by mail would be unable to implement the interventions due to changing circumstances in their own life or that of the care recipient. Follow-up calls or visits by the care coordinator or the project coordinator were instituted to assist in these cases.
- Care coordinators who carry a heavy caseload of clients appreciated that the project coordinator could implement the requested interventions, which in some instances required considerable time and effort. The project coordinator stepped in only when requested by the care coordinator, and did not communicate directly with the caregiver except with the consent of the care coordinator.
- Transitions can be stressful for caregivers and can add significantly to their burden. Care coordinators were encouraged to discuss changing circumstances with the caregiver, and if appropriate to submit revised care plans, for example to reallocate adult day program fees to cover short-term transportation for hospital visits. But where circumstances changed permanently such that the caregiver would no longer be required to provide care at home, unexpended funds for services or equipment ceased to flow.

3.5 Costs of care plan interventions

The project budget envisioned average costs of \$1,500 per care plan. Caregivers recruited in Phase 1 and continuing into Phase 2 (36 caregivers to date) could thus potentially receive \$3,000 or more. Total direct expenditures on care plans were budgeted at \$450,000 for 300 caregivers.

In Phase 1 some care plans specified equipment interventions that significantly exceeded the expected average. A hospital bed, for example, could cost \$4,000. This type of intervention was usually approved on the assumption that other care plans would cost less than the average, which seems to have been the case. In Phase 2, care plans were capped at a maximum of \$1,500 per caregiver. Costs were monitored closely in Phases 1 and 2 to avoid an upward funding trend.

The table below categorizes intervention types, and contrasts the percentage of caregivers opting for those interventions with the actual cost of the interventions.

Interventions Requested in Care Plans

| | Requested | % Spent | \$ Spent |
|---|-----------|---------|-------------------|
| Informal respite care (relative, friend, neighbour, etc.) | 31% | 23% | \$ 95,623 |
| Personal support worker | 22% | 16% | \$ 65,629 |
| Equipment | 19% | 10% | \$ 41,410 |
| Bill payment | 15% | 10% | \$ 40,060 |
| Health care supplies | 25% | 10% | \$ 41,868 |
| Physiotherapy | 16% | 7% | \$ 28,975 |
| Social activity / self-care | 20% | 5% | \$ 21,154 |
| Adult day program | 10% | 6% | \$ 23,907 |
| Short-stay respite | 7% | 4% | \$ 17,335 |
| Transportation | 15% | 4% | \$ 16,220 |
| Home help (Meals on Wheels, cleaning services) | 12% | 5% | \$ 18,738 |
| Total funds spent to date to implement care plans | | | \$ 410,919 |
| Average spending per caregiver (n = 281) | | | \$ 1,462 |

Note that although 31 per cent of caregivers opted for informal respite care, the proportion of funds spent on this intervention was just 23 per cent. This may be because the cost per hour of hiring a relative, friend or neighbour averages \$20, whereas the cost of a personal support worker supplied by an agency averages \$35 per hour - the number of hours almost doubles for virtually the same expenditure if relatives, friends or neighbours are hired to provide respite care.

Certain often-requested interventions can be delivered in a more cost-effective way if the project office aggregates the requests into a service contract with a supplier. For example, because the high cost of incontinence products concerned many caregivers, the project coordinator contracted with dedicated suppliers to deliver products directly to the home of the care recipient, at a wholesale price. This had a two-fold benefit for caregivers: they were relieved of the need to go the store to pick up incontinence supplies, and the overall financial burden was lowered, which for some had been upwards of \$180 per month.

4. What Have We Learned So Far?

4.1 Findings: The Evaluation Process is Ongoing

The evaluation strategy for this project called for multiple qualitative and quantitative data sources to measure the impact of the interventions on caregivers and on the system of care. Sources of data would include:

- A targeted literature review, policy scan and interviews with key informants (complete)
- Administrative data describing key characteristics of all participating caregivers, and the type and amount of services they received through the project (ongoing)
- RAI-HC and ED Notification data from TC-CCAC for all clients in the SEC program (complete)
- RAI-HC and ED Notification data from TC-CCAC clients in the project (ongoing)
- RAI-CHA and Distress Scale data from other agencies partnering in the project (ongoing)
- Debriefing sessions with care coordinators (ongoing)
- One-minute evaluations forms completed by caregivers (ongoing)
- Evaluative interviews with 17 caregivers conducted by the Reitman Centre (complete)

The need for formal ethics approval was anticipated at the start of the project but was not pursued because of the terms outlined by project partners at that time. Ultimately ethics approval became necessary. As a result, the secondary analysis of the data was significantly delayed. Due to this delay, the bulk of RAI data could not be analysed until June 2012, and represented only 91 caregivers out of 282 recruited for the project to date. The one-minute evaluations were mailed to 150 caregivers in March 2012, with 131 forms completed and returned as of May 2012. The hope is that another round of surveys will be sent out in August 2012, contingent upon the release of final funding. Because of this, the evaluation must be viewed as descriptive and preliminary.

4.2 Findings: The Caregivers

One-minute evaluation forms were returned by 156 caregivers from Phases 1 and 2 - the **average satisfaction score as of June 25, 2012 was 8.8 out of 10**. It is obvious that caregivers appreciate this project. But because of the complexity of their situations, it is not possible at this stage to determine if project interventions actually achieved the goal of relieving caregiver stress. Nevertheless, the Balance of Care team, by analysing RAI and ED data for all SEC clients

against the 91 clients in this project obtained six months prior to December 2011, found relevant evaluative information concerning the caregivers at baseline, with highlights summarized below:

PRE-INTERVENTION

- Caregivers in this project are more likely than all SEC clients to be female and to speak English. Almost half come from minority groups.
- Caregivers in this project are more likely to live with the person they are caring for, and more likely to be their spouse rather than their adult child or child-in-law.
- Virtually all caregivers in this project were observed by their care coordinator to be in financial need.
- Compared to all clients in the SEC program, caregivers in this project are caring for seniors with higher needs: the care recipients are more likely to score higher on the MAPLe scale of needs, more likely to score in the highest category of difficulty on the IADL scale, and more likely to experience high needs with the activities of daily living ADL hierarchy scale.
- Seniors cared for by caregivers in this project are more likely than other SEC clients to have cognitive difficulties, with fully 60% scoring in the severe impairment range, and they are more likely to demonstrate behaviour problems (verbal or physical abuse, or behaviour needing intervention).
- All are eligible for long term care placement

And yet in spite of their demonstrated higher needs, clients in this project do not receive significantly more formal care than other SEC clients. In fact, any additional care they need must (and does) come from their informal caregivers, mostly spouses living with them at home.

- Caregivers in this project spend more time per week providing care than other SEC caregivers (approx. 50 hours vs. 30), and they provide more help with IADLs and with ADLs.
- Caregivers in this project score higher on indices associated with stress and distress: they are more likely to state that they are unable to continue caring (29% vs. 16%) and to express feelings of distress, anger or depression (65% vs. 35%). *Note: This data suggests that access to counselling (as provided for in the CCAC/Alzheimer Society Interprofessional project) might be useful for caregivers to teach them coping techniques and reduce their feelings of stress and isolation.*
- There is no statistically significant difference in the mean number of ED admissions for clients in this project compared to all SEC clients. And yet one would normally expect more ED admissions from project clients because of their higher levels of debilitation. It is possible that their ED admissions are not higher because their caregivers are more likely to provide more hours of care than other SEC caregivers, suggesting that more hours of informal care helps to mitigate ED admissions.

In addition to the RAI data provided by the TC-CCAC, the Balance of Care team were able to analyse 131 one-minute evaluation forms that had been mailed to caregivers and returned by them to the project office. These forms account for the effects of the intervention at the point at which caregivers returned the survey. Highlights of the analysis are summarized below:

POST-INTERVENTION

- In response to the one-minute evaluation question about the most important issue (or problem) that they face in their caregiving role, caregivers identified a range of issues including the emotional, social, physical or financial impact on them, the high needs of the seniors receiving care, the lack of formal and informal support, and the lack of time.
- Caregivers have complex needs, and must navigate a complex system of supports. Many respondents highlighted problems and frustrations that they face on a daily basis related to the complexity of their situation.
- Asked what they would need to continue caregiving, respondents identified “more support” as the primary requirement for continuing. The type of support ranged from counselling, funding, and more hours to pursue various things like employment, respite and time for themselves. The idea of “more support” seems simple but in fact highlights the complexity of individual situations. The caregiving role impacts on caregivers differently, and therefore the outcomes of supports will vary based on the individual circumstances.
- Asked if this project helped them and the person they care for, all but three respondents were positive and supportive, frequently using words such as ‘helpful’, ‘assistance’, ‘support’, ‘thank’ and ‘appreciate’. They highlighted that the project had a positive impact on them because it allowed them greater control over their own lives, reduced stress, improved their financial situation, improved their ability to take care of themselves, and ultimately improved their relationship with friends, family and the person they were caring for.
- Responses to a question about what they liked most and least about the project, and what they would change, showed that 21 caregivers liked everything about the project and would change nothing, and 24 respondents suggested that, if possible, the project should be maintained for the longer term. Negative feedback was rare and at times not specific to this project, but rather a response about the overall complexity of the health care system.
- In our Caregiver Framework for Seniors demonstration project, almost one in three at-risk caregivers requested “informal respite care” which allowed them to hire relatives, friends or neighbours to care for the person they were caring for. In Toronto’s diverse community, being able to hire a paid caregiver who comes from the same ethno-cultural community and who might already be known and trusted by the high-needs client is a great financial and emotional advantage.

4.3 Findings: The Care Coordinators

The Balance of Care team conducted two waves of debriefing sessions with TC-CCAC care coordinators participating in the project, in order to identify, document and continuously learn from the issues they encountered and the experience they gained ‘on the front lines’.

The first wave of debriefing sessions was conducted between October 31 and December 22, 2011. The second wave began on June 14, 2012, and is expected to continue through summer 2012, depending on availability of funds to continue the project to its completion. More

detailed findings from the debriefing sessions can be found in *Phase 1 Year-End Report* submitted to TC-LHIN on March 31, 2012, and in the attached Evaluation Interim Report.

Highlights of the debriefing sessions include:

- From their normal caseload, care coordinators were asked to recruit three to five of their caregivers who met the project eligibility criteria. With few other instructions on which caregivers to select, care coordinators considered many factors in their selection, including family support available to the caregivers, observed financial need, cultural barriers, and caregiver risk of mental and physical problems. Care coordinators may thus have selected for project assistance the most at risk caregivers in the most difficult circumstances.
- Phase 1 care coordinators valued the flexibility they had in negotiating the care plan with the caregiver. They placed high value on the counselling aspect of the project, and appreciated the problem solving approach that encourages self-management of funds by the caregivers.
- Phase 1 care coordinators speculated that potential impacts of the project might include extending for a longer period the caregiver's abilities to continue in this role, reducing the number of crisis applications for long term care, improving the social, emotional and physical needs of the caregivers and reducing the caregiver burden on measurement scales.
- By the second phase, care coordinators had become more familiar and more comfortable with 'creative' services such as recreational activities, and self-care supports (such as massages) that are not typically offered in the TC-CCAC basket of services.
- Follow-up visits with caregivers were easier than the initial visit when they had first introduced the Caregiver Framework project, perhaps because the caregivers had become more comfortable focusing on their own needs and receiving services benefiting them rather than the person they were caring for. Because of this, they were better able to articulate which services helped to relieve their caregiving burden.
- Care coordinators unanimously agreed that this project has a positive impact on caregivers, who feel more knowledgeable about services that can help them, more empowered, and more appreciated and validated in their caregiving role. This is gratifying because at-risk caregiver often feel alone and unappreciated by other family members, and by the person they are caring for, particularly if dementia is present.
- Care coordinators also believe that care recipients benefit from this project because their caregiver provides better care as a result of the reduced stress brought about by project interventions.
- Concerning their own role in this project, care coordinators said they feel good about being able to provide almost immediate support to caregivers, thanks to the expediency and efficiency of the project office, especially compared to the reality of most services they normally administer which tend to have long waiting lists. And while admitting that the problem solving sessions with caregivers increase their workload, they feel that the conversations with caregivers are important and of direct benefit.
- Finally, when asked about the potential impact of this project on the health care system, care coordinators believe that the project approach and its interventions do increase the capacity of caregivers to continue in their difficult caregiving role, leading to perhaps

significant delays in admission to long-term care, and over time generating significant savings for the health system. The care coordinators ventured that even if the project ends and funds and flexible services are no longer available, the caregivers who took part in the project will continue to benefit from the experience.

Care coordinators from the TC-CCAC and (after February 2012) from the seven other agencies involved in this project, provide an invaluable perspective in the evaluation exercise. Their strong positive response to two critical aspects of the project: the Problem Solving Therapy approach and the flexible innovative interventions, validate the goals of the project in a way that the theoretical framework and the caregiver responses could not do alone. The project is immensely grateful to the care coordinators who work on the front lines to keep seniors aging at home for as long as possible, able to call on all the community supports that a caring society can provide.

4.4 Findings: About the Project Itself

The findings relating to the project itself are based on an analysis of all sources of data available to the project at this time, including the targeted literature search, but the opinions voiced and the conclusions drawn must be seen as descriptive and preliminary. Further analysis would add more strength to measuring the project goal to increase the resiliency of at-risk caregivers so that they are better able to continue to care for a family member at home.

- The policy context, particularly regarding the allocation of financial and human resources to support high needs seniors cared for at home by at-risk informal caregivers, is complex and constantly changing, so much so that it may be impossible to prove a direct causal link between improved caregiver resiliency and the *Aging at Home* and *Action Plan for Health Care* policy goals of ensuring that seniors stay at home as long as reasonably possible, reducing ED admissions and ALC days, and delaying placement in long term care. And yet a growing weight of international evidence emphasizes the crucial role of informal and mostly unpaid caregivers, not only in maintaining the independence, well-being and quality of life of cared-for older persons, but in moderating their use of costly and increasingly stretched hospital and institutional resources.
- This project has incorporated methods to target and identify caregivers not currently seeking services through CCAC, successfully aligning with several strategic partners in order to reach the most vulnerable caregivers. At-risk caregivers, who are not accessing any support services whatsoever, likely because of a language barrier, remain to be targeted.
- A common feature of caregivers in this project is that they are caring for clients with needs that are demonstrably higher than the total SEC client population, itself already identified as having higher than average needs. And while clients in this project do not appear to receive more formal services than other SEC clients, they do receive more informal care, particularly from spouses living with them, spouses who may themselves be frail and suffering from ill health. This suggests not only why informal caregivers may be experiencing high levels of stress that put them at risk of burnout, but also points to the crucial role that caregivers play in keeping the high-need senior at home for as long as possible. These findings validate

the project goal of increasing the resiliency of at-risk caregivers so that they can extend the duration of their difficult caregiving role.

- This project is particularly noteworthy because it does not offer fixed services or benefits, but rather establishes a ‘platform’ for negotiating flexible support packages which meet the needs of individual caregivers in their individual circumstances. This platform might better be characterized as ‘supported self-management’ in which caregiver decisions are assisted by professional case managers who understand support options and how to access them.
- This project has notable similarities with the *Cash and Counselling* project in the U.S.A. One particular finding of that project is that caregivers who were able to exert greater control over their care were significantly more satisfied with, and worried less about the overall care that they received, and were less likely to report emotional, physical or financial strain than caregivers who were limited to a specific basket of services.
- This project encourages the care coordinator and the caregiver to be creative and to think “outside the basket” of the usual community supports. We have been gratified that the negotiated interventions span a wide range, and that some are notably unconventional. And while we may not yet understand the impact of these interventions on different caregivers in their different circumstances, the process of negotiating the care plan has been shown to build a stronger link between the care coordinator and the caregiver – a fact that is recognized and appreciated by both.
- Caregivers in this project are taught to focus on the causes of their stress and they have direct input in devising the intervention that the project will fund. They therefore have a higher stake in its success. Already at high risk of burnout, and in light of the time-limited nature of the project, caregiver stress levels may not be reduced in the long term, but the crucial role of the caregiver is acknowledged, and they are given a financial and emotional boost to assist them in their difficult caregiving role. These are important measures of success in and of themselves.

5. What Should Happen Next?

Recommendation 1.

Connect care coordinators and caregivers with additional resources in the community (such as disease- specific charities) for more in depth counselling, support and education, addressing an unmet need clearly identified in this project.

The *Caregiver Framework for Seniors* demonstration project is a ground-breaking initiative aimed at supporting at-risk informal caregivers of older persons with high needs. Particularly noteworthy is the project approach which, instead of offering the usual basket of fixed services, establishes a platform for negotiating flexible support packages that reflect the individual circumstances of the caregivers and the persons that they are caring for.

- The initial problem solving dialogue between the care coordinator and the caregiver is critically important. The stressors of caregiving are multiple and often intertwined. Understanding and then prioritizing the root causes of stress are essential in negotiating interventions that might prove most helpful to the at-risk caregiver. In this project, the specially-trained care coordinators provide valuable guidance as caregivers are asked to describe the things that worry them most in their caregiving role. This focus on the caregiver’s own circumstances and state of mind builds strong links between them and their care coordinator, who is seen to directly address their concerns and value their opinion.
- This project delivers care plan interventions that are tailored to meet individual needs. The usual basket of services offered by the TC CCAC greatly limits the flexibility of interventions, whereas this project encourages care coordinators and caregivers to think “outside the basket” and devise creative ways to relieve caregiver stress. That some interventions were notably unconventional validates the project approach of granting significantly more discretion to care coordinators than they would normally enjoy. This platform approach may also prove valuable in the further program development that is meant to target at-risk caregivers. Care coordinators appreciated the trust that was placed in them, and the minimal paperwork requirements of this project, which allowed them to spend maximum time with their client, resulting in more thoughtful and creative individualized care plans.
- Care coordinators carry a heavy caseload and could not always activate or carefully monitor the sometimes complex interventions that had been agreed in the individual care plans. On request, the project coordinator was able to step in and assume this role, and where numbers warranted, was able to negotiate contracts with suppliers to improve efficiencies and generate cost savings.
- Financial assistance in the form of cash is a novel element of this project. But the cash on its own is not a complete solution to the complex problems of caregiving – it must be accompanied by careful understanding of the caregiver’s situation, thoughtful guidance from a trained and experienced care coordinator, and where appropriate, efficient and effective administrative support from the project coordinator’s office. These characteristics of the project should be retained and expanded going forward.
- Current restrictions on TC-CCAC-funded personal support workers, for example, are a barrier that could be eliminated if caregivers are truly to be consulted in the type of intervention that could help them. Many other findings in this demonstration project have practicable applications that can be extended to improve the current system of care supporting at-risk caregivers caring for a high-needs senior at home.

Recommendation 2.

We recommend that TC LHIN, TC CCAC and the Alzheimer Society of Toronto initiate discussions to take the best lessons learned in this project, and embed them in the SEC program so that they can be applied to the entire population of at-risk caregivers of SEC clients.