

Caregiver Support Project: Formative Evaluation

Final Report

Submitted to:

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Executive Summary

1.0 Caregiver Support Project (CSP)

The Caregiver Support Project (CSP) is a ground-breaking initiative aimed at assisting “at risk” informal caregivers – family, friends and neighbours – of older persons with high needs. It responds to a growing weight of international evidence pointing to the crucial role that informal, mostly unpaid, and mostly female caregivers play in maintaining the independence, well-being and quality of life of older persons, while moderating use of costly and increasingly stretched hospital and institutional resources.

The CSP is led by the Alzheimer Society of Toronto (AST) in partnership with the Toronto Central Community Care Access Centre (TC CCAC) and seven community support service agencies (CSSA). It is funded by the Toronto Central Local Health Integration Network (TC LHIN).

Under the CSP, specially trained home and community care (H&CC) care coordinators (also known as case managers) identify “at risk” caregivers of “high needs” older persons. They use budgets averaging \$1500/caregiver/year to engage caregivers in a process of problem identification and problem solving, leading to the creation of flexible care packages tailored to individual circumstances, needs and preferences.

2.0 Formative Evaluation

In August 2011, the Balance of Care Research and Evaluation Group (the “evaluation team”) was commissioned by AST to evaluate the CSP. We framed our evaluation as “formative” -- we focused on gathering and analyzing the best available qualitative and quantitative evidence to document project design and implementation, facilitate continuous improvement as the project rolled out, and identify outcomes for future evaluation.

To ensure that our evaluation conformed to high standards of ethical research, we sought and received ethics approval from The University of Toronto Health Sciences Research Ethics Board (REB) and the Joint Bridgepoint Health-West Park Healthcare Centre-Toronto Central Community Care Access Centre-Toronto Grace Health Centre Research Ethics Board (JREB).

3.0 Findings

3.1 Context

Our environmental scan found:

- Growing research and policy interest in informal caregivers who provide the bulk (70 to 90%) of the care required by older persons to keep them independent, thereby moderating demand for costly hospital and institutional care
- A growing range of caregiver support initiatives across the industrialized countries and within Ontario including respite, care navigation, employment opportunities, extended

benefits, unpaid leave, caregiver allowances and weekly payments, counselling, information and referral

- Little systematic evaluation of outcomes or hard intelligence to guide the design and implementation of caregiver support initiatives
- Strong alignment between the CSP and key policy priorities and directions including Ontario's *Seniors Strategy* and its *Action Plan for Seniors*.

3.2 Caregiver Characteristics

CSP administrative data confirmed that caregivers in the CSP had multiple risk factors.

Caregivers:

- Were often older persons themselves, averaging 65.8 years of age
- Were predominately female (77.1%)
- Often spoke a language other than English (29.5%)
- Often self-identified with minority communities (46.9%)
- Were judged by TC CCAC care managers to be in financial need (96.5%).

3.3 Caregivers and Cared-For Older Persons

Home care assessment (RAI-HC) data confirmed that cared-for older persons in the CSP had high needs even in comparison to older persons in the Seniors Enhanced Care (SEC) program (themselves among the highest need clients of the Toronto Central Community Care Access Centre (TC CCAC)).

- A majority of CSP clients spoke a language other than English (57.1%)
- About a third recorded "very high" MAPLe (Method for Assigning Priority Levels) scores (37.1%)
- Almost two thirds (60.7%) were dependent on others to perform ADLs (activities of daily living) such as eating, personal hygiene, locomotion, or toilet use
- Almost two thirds (61.4%) scored in the severe impairment range of the Cognitive Performance Scale
- One in seven (14.6%) expressed disruptive or aggressive behaviors, and one in 15 (6.7%) were physically abusive.

Home care assessment data showed that:

- About a third of caregivers (29.2%) stated they were unable to continue caring
- About two thirds (65.2%) expressed feelings of distress, anger or depression
- Seven in ten (70.3%) were "distressed".

Nevertheless, informal caregivers in the CSP:

- Provided 35 hours of care during the week and 15 hours on weekends
- Were still willing to increase the amount of time they spent in caregiving
- Did not receive significantly more home care hours.

3.4 TC CCAC Care Coordinators' Debriefing Sessions

Findings from two waves of debriefing sessions with TC CCAC care coordinators revealed strong support for the CSP. In addition, care coordinators observed that:

- When selecting participants, a range of factors should be considered including available family supports for caregivers themselves; the presence of linguistic/cultural barriers; and the risk of mental and physical health problems for caregivers
- The CSP's flexibility allowed innovation
- The counselling aspect of the CSP equips caregivers to take control of their lives and avoid crisis over the longer term
- The CSP generates multiple, albeit, sometimes hard-to-quantify benefits for caregivers, care coordinators, and the health care system, including maintaining caregiver resilience and ability to care
- The CSP results in cost savings by avoiding emergency hospital and LTC crisis admissions
- The CSP should be a standard component of care for all high needs older persons.

3.5 CSSA Care Coordinators' Debriefing Session

Our debriefing session with CSSA care coordinators also revealed strong support for the CSP. CSSA care coordinators noted that:

- Selection criteria should be expanded to include caregivers who are tired, fatigued, have minimal financial and social resources (including education and English language ability), or have "maxed out" available support services
- The CSP's counselling and support functions build long-term capacity
- Caregivers needed to know that the CSP would continue.

3.6 Caregiver One Minute Evaluations

Comments from 360 one-minute evaluations returned by caregivers revealed high levels of satisfaction with the CSP.

Caregivers identified three interrelated sources of stress:

- Stress related to the care needs of older persons
- Stress related to caregiver capacity
- Stress related to challenges accessing formal services.

They acknowledged the CSP's contributions in 3 key areas:

- Finances – the CSP helped with financial stability
- Time for themselves – caregivers could engage socially and care for their own health
- Time for others – the CSP allowed caregivers to re-connect with family and friends.

"Most liked" aspects of the program included:

- Administration was simple (few forms and red tape)
- Financial assistance allowed them to pay for help

- Having access to needed supports gave them “a so deserved break”.
- The project gave them “peace of mind”
- Knowing that their loved ones were being cared for – this allowed them to go out to work or run errands.

“Least liked” aspect included:

- Filling out forms
- Obtaining receipts.

3.7 Administrative Overhead

In addition to the direct costs of providing supports and services to caregivers, the CSP logged additional costs associated with start-up and ongoing administration.

For example, the initial round of training for care coordinators cost just under \$40,000. Ongoing administration, including the effort expended to procure needed supplies and services, and to track scores of individual invoices for individual caregivers, had an estimated cost of \$141,500 annually.

Moving the project toward a “pre-payment method” in which caregivers are provided with a cheque in advance, instead of tracking invoices and then reimbursing, could save effort.

4.0 Conclusions

Although simple in concept, the evaluation emphasizes that the CSP is a complex intervention encompassing multiple stakeholders and outcomes over short and longer-terms. It also shows the formidable challenges that may be faced by caregivers as they work to keep their loved ones at home.

The CSP directly addresses caregiver need. Using a relatively modest dollar investment, it equips care coordinators to engage “at risk” caregivers of high needs older persons in a process of problem-identification and problem-solving, aiming not only to manage immediate crisis but to build longer-term resilience and capacity. In doing so it pushes beyond conventional thinking and action.

The CSP is strongly aligned with key research and policy directions. It:

- Formally recognizes the crucial role of caregivers who provide the bulk of the care for community-dwelling older persons as “clients” in their own right
- Focuses on at risk caregivers and high needs older persons who are, or who could become, high health care utilizers; the RAI-HC data confirm that CSP participants had higher needs even than SEC clients who themselves are LTC eligible
- Builds community-based capacity by equipping caregivers and care coordinators to mitigate short-term crisis, and sustain informal caregiving
- Strengthens linkages between providers, thus contributing to greater system integration.

There was strong support for the CSP among participants. For example,

- Care coordinators overwhelmingly approved of, and supported the CSP. They valued its flexibility, the opportunity it gave them to engage caregivers and find out what would make a real difference for them and cared-for persons, over short and longer terms.
- Caregivers reported that as a result of the CSP, they were better able to carry the financial and personal burden of caregiving; they had more time for themselves, were able to reconnect with family and friends, and had more control over their lives.

5.0 Recommendations

Recommendation 5.1. Sustain, scale-up and spread the success of the CSP. In addition to managing crisis and improving the quality of life of caregivers and cared-for older persons in the short term, the CSP builds capacity and helps avoid crisis over the longer-term, with clear benefits for people and the health care system.

Recommendation 5.2. Broaden inclusion criteria to reach caregivers before crisis occurs. Targeting caregivers earlier before they are “at risk” can increase the opportunity proactively to avoid as well as manage crisis.

Recommendation 5.3. Recognize the caregiver as an essential part of the “unit of care” in home and community. By recognizing informal caregivers as “clients” in their own right and full partners in care, current caregivers are better able to continue to care, and future caregivers may be persuaded that this crucial role has merit and is doable.

Recommendation 5.4. Continue to encourage flexibility. The CSP uses a modest dollar amount to engage caregivers in what we have referred to as “supported self-management;” caregivers drive allocation decisions with the advice and support of professional care coordinators who can help them assess challenges, and find the best available solutions.

Recommendation 5.5. Establish a transparent accountability framework. An explicit accountability framework could include resource allocation guidelines and streamline administration. One option might be to provide caregivers with cash installments based on a care plan negotiated, in accordance with guidelines, in conjunction with the care coordinator, and attainment of plan goals; expenditures would then be subject to audit after the fact.

Recommendation 5.6. Spread the CSP through Health Links. There are good precedents. One example is *First Link*, a collaborative initiative between primary care providers and Alzheimer Societies which ensure that persons with dementia and caregivers are referred to specialized services as soon as possible after diagnosis; *First Link* was recently identified by Ontario’s Seniors Strategy Lead as a best practice to be spread across the province. The CSP offers opportunity to engage caregivers and older persons with a broader range of needs which put them “at risk.”

Recommendation 5.7. Encourage inter-disciplinary, inter-organization team approaches. Even as the CSP forges stronger partnerships at the organization level, it can also encourage the emergence of inter-disciplinary, inter-organization care teams. Given that caregivers emerge from diverse communities, and have needs that span multiple fields including health and social care, education, housing, transportation and income support, team approaches seem to be particularly well suited.

Recommendation 5.8. Partner with researchers to demonstrate outcomes. While it was outside of the scope of this evaluation to measure outcomes, participants identified a range of qualitative and quantitative benefits for stakeholders that could and should be measured in the future. One workable option may be to partner with academic researchers who would receive access to CSP data in exchange for securing research funding.

Caregiver Support Project -- Formative Evaluation Final Report

1.0 Caregiver Support Project (CSP)

The Caregiver Support Project (CSP) is a ground-breaking initiative aimed at assisting “at risk” informal caregivers – family, friends and neighbours – of older persons with high needs. It responds to a growing weight of international evidence pointing to the crucial role that informal, mostly unpaid, and mostly female caregivers play in maintaining the independence, well-being and quality of life of older persons, while moderating use of costly and increasingly stretched hospital and institutional resources. It also responds to growing concerns that as caregiver burden increases, due in part to population aging, caregiver stress and burnout will also increase, eroding capacity and resilience.

The CSP is led by the Alzheimer Society of Toronto (AST) in partnership with the Toronto Central Community Care Access Centre (TC CCAC) and seven community support service agencies (CSSA). It is funded by the Toronto Central Local Health Integration Network (TC LHIN).

Under the CSP, specially trained home and community care (H&CC) care coordinators (also known as case managers) identify “at risk” caregivers of “high needs” older persons. They use budgets averaging \$1500/caregiver/year to engage caregivers in a process of problem identification and problem solving, leading to the creation of flexible care packages tailored to individual circumstances, needs and preferences. While similar in key respects to “self-management,” in the sense that caregivers themselves play a major role in determining the best use of resources, the CSP is better characterized as “supported” self-management, since caregiver decisions are informed by professional care coordinators who understand available support options, and by CSP staff who access and pay for agreed-upon services and supports.

Initiated in (October) 2011 as a time-limited experiment, the CSP is now approaching the end of its second fiscal year (March 2013) with funding confirmed for 2013-14.

During its 18 months in operation, the CSP has:

- Provided support to a total of 258 “at risk” caregivers, 41 of whom received care packages in its first and second years.
- Grown to include 8 H&CC providers serving diverse communities
- Encompassed a range of health and social supports including education, counseling, peer support, in-home help, respite, personal care, transportation, medical supplies and equipment, and health promotion and wellness care.

2.0 Formative Evaluation

In August 2011, the Balance of Care Research and Evaluation Group (the “evaluation team”) at the University of Toronto, was commissioned by AST to evaluate the CSP. Details of our approach and preliminary findings are presented in two interim reports:

- Caregiver Support Project: Formative Evaluation Preliminary Results, submitted to AST, January 13, 2012
- Caregiver Support Project: Formative Evaluation Interim Report, submitted to AST, June 25, 2012.

Without repeating the substance of these previous reports in any detail, it is important to note that we framed our evaluation as “formative” -- rather than engaging in primary data collection and measuring a set of pre-determined outcomes, we focused on gathering and analyzing the best available qualitative and quantitative evidence to document project design and implementation, facilitate continuous improvement as the project rolled out, and identify outcomes for future evaluation.

2.1 Evaluation Design Considerations

Our choice of formative evaluation, and the evaluation design, considered multiple factors including:

- **The evidence is inconclusive.** A growing number of reports and policy documents nationally and internationally make a strong case for public provision of caregiver supports on moral/ethical and cost-effectiveness grounds. However, there is relatively little practical guidance on what works best for which caregivers in what contexts.
- **Causal relationships are unclear.** While it is often assumed that caregiver stress and “burnout” are a direct function of the needs of cared-for persons -- with higher needs leading to higher levels of stress -- caregivers may also be impacted by a range of external factors including access to needed formal services. Cultural perceptions about the role of women, and the responsibilities of families, can play a powerful role in shaping caregiver roles and burden.
- **Multiple qualitative and quantitative outcomes may accrue to multiple stakeholders over different time frames.** Research and policy documents point to a range of possible benefits for different stakeholders including decreased stress and improved resilience for caregivers; improved quality of life and independence for cared-for older persons; and moderated health care costs due to reduced demand for formal care including hospitals and residential long-term care (LTC). However, such benefits may occur in different measure, over different time periods. Moreover, some benefits (e.g., crisis management) may be immediate; others (e.g., establishment of self-sustaining

caregiver support networks) may occur over a longer time horizon.

- **Caregivers and cared-for persons are not homogeneous groups.** Caregivers come in an infinite variety of shapes and sizes, and they support older and younger persons with a range of different health and social needs. The literature emphasizes that caregivers may be spouses, children, friends and neighbors who devote more or less time to caregiving and provide a varying mix of instrumental and emotional supports, in addition to accessing and coordinating needed formal services on behalf of cared-for older persons.

2.2 Evaluation Components

While such complexities do not preclude rigorous evaluation, they suggest the need for a nuanced and multifaceted approach. Here, we draw on the influential work of the Medical Research Council in the UK (2008) which emphasizes that complex interventions (like the CSP) require complex evaluations which consider a range of outcomes for different stakeholders, access qualitative and quantitative evidence, and take context into account (for details go to www.mrc.ac.uk/complexinterventionsguidance).

Since the evaluation budget and time frame did not permit extensive primary data collection, we aimed to make the best use of available quantitative and qualitative data sources.

2.2.1 Ethics Review and Data Sharing Agreement

“At risk” caregivers of high needs older persons on the verge of loss of independence easily fit within definitions of a “vulnerable” group.

To ensure that our evaluation conformed to high standards of ethical research, and did not pose additional risks, we sought and received ethics approval for evaluation components involving human subjects including:

- Secondary analysis of anonymized TC CCAC RAI-HC (Resident Assessment Instrument – Home Care) data for caregivers and cared-for older persons
- Secondary analysis of anonymized data collected by AST as part of the administration of the project including descriptive information on caregivers and caregiver support packages, as well as anonymized caregiver responses to “one minute evaluations”
- Analysis of the results of qualitative “debriefing” sessions with front-line care coordinators engaged in the CSP.

Ethics approval was obtained from two sources:

- The University of Toronto Health Sciences Research Ethics Board (REB) -- April, 2012
- The Joint Bridgepoint Health-West Park Healthcare Centre-Toronto Central Community Care Access Centre-Toronto Grace Health Centre Research Ethics Board (JREB) -- May 2012 (required by the TC CCAC).

We also negotiated a formal Data Sharing Agreement with the TC CCAC, signed in June, 2012. Among conditions meant to protect sensitive client information, this agreement restricts

disclosure or transfer of assessment and utilization data, requires appropriate safeguards against the identification of individuals or unauthorized use, and prohibits direct contact with TC CCAC clients.

2.2.2 Environmental Scan

We conducted a scan of the research and policy context for the CSP. This included:

- A targeted review of the published and grey literatures on caregivers and caregiver supports from leading international sources (e.g., the Organization for Economic Cooperation and Development – OECD) and Canadian sources (e.g., the Canadian Institute of Health Information (CIHI), Health Council of Canada, St. Elizabeth, and Conference Board of Canada).
- Key informant interviews with representatives of caregiver support projects and caregiver associations in Canada including:
 - Wesway – Family Directed Respite Program, Thunder Bay, Ontario
 - Nova Scotia Department of Health and Wellness – Caregiver Benefit Program
 - Nova Scotia Department of Health and Wellness – The Supportive Care Program
 - VHA Home Healthcare - Ring and Reach Program, Ontario
 - Victoria Order of Nurses – SMILE Program, southeast Ontario
 - Family Service Toronto – Individualized Funding Program
 - Veterans Affairs - Veterans Independence Program (VIP)
 - Ontario Caregiver Coalition
- A rapid review of the policy environment in Ontario. We were particularly interested in the extent to which the CSP aligns with key policies such as the Aging at Home Strategy; Ontario’s Action Plan for Health Care; and more recently, Ontario’s Seniors Strategy and the provincial Action Plan for Seniors.

2.2.3 Secondary Analysis of CSP Administrative Data

Caregivers are at the core of the CSP, and as such, their experiences and perceptions are essential. Yet, early discussions with AST and TC CCAC staff emphasized that evaluation methods such as surveys, or personal interviews conducted by unfamiliar personnel, could increase stress and burden, particularly if caregivers feared (even if such fears were unfounded) that critical responses could result in a loss of service.

As a result, the formative evaluation relied on secondary analysis of information generated as part of the administration of the CSP:

- Initial CSP assessment and care plans completed by care coordinators
- “One minute evaluations,” brief, open-ended, anonymous questionnaires completed and returned directly to AST by caregivers.

Assessment and care plan forms recorded basic descriptive information about caregivers (e.g., age, language, and ethnicity) as well as mix and volume of supports provided through the CSP.

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A first anonymized cut of these data was received in December, 2011; analysis was commenced upon receipt of ethics approval. A second cut was received in October 2012.

As detailed in Appendix A, Time 1 one-minute evaluation asked about:

- Relationship to the care recipient (e.g., husband, wife, friend)
- Care provided in a typical day
- The most important issue or problem faced as a caregiver
- What caregivers needed to continue caregiving
- How well the CSP supported met the caregiver’s needs
- Satisfaction with the CSP
- Current level of stress.

Time 2 one-minute evaluations (for details see Appendix B) asked about:

- What caregivers liked most/least about the CSP
- How the CSP had impacted on the caregiver and care recipient
- What, if anything, the caregiver would change about the CSP
- Satisfaction of the CSP
- Current level of stress.

A total of 216 caregivers responded to the one-minute evaluation at Time 1; 144 caregivers responded to the one-minute evaluation at Time 2. However, these data were often incomplete. Not all caregivers returned evaluations, and even those that did, did not always complete them.

We used Nvivo9 to assist in the identification of themes in caregivers responses. Where possible, we also compared Time 1 versus Time 2 stress and satisfaction ratings.

Our analysis and interpretation of these data was enriched by regular meetings and consultations with CSP staff, particularly the Project Coordinator, who provided valuable insight challenges experienced as the project rolled out.

2.2.4 Secondary Analysis of TC CCAC RAI-HC and ED Notification Data

Initial waves of CSP caregivers were recruited through TC CCAC care coordinators from the ranks of their SEC (Seniors Enhanced Care) clients; the SEC program provides high needs older persons at risk of institutionalization with intensive case management and enhanced services.

Although caregivers are technically not TC CCAC clients, the CSP enrolled caregivers of high needs older persons who were TC CCAC clients, and who had received a full-scale assessment using the RAI-HC (Resident Assessment Instrument – Home Care), a widely-used assessment tool. In addition to generating extensive information on the characteristics and needs of older persons, RAI-HC assessments gather important (albeit limited) information about “informal support services” (Section G) including ability of the caregiver to continue to provide care.

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Working within available budget resources, we used a standard statistical package (SPSS) to conduct basic descriptive analysis of RAI-HC data which aimed to:

- Describe key characteristics of TC CCAC clients and caregivers participating in the CSP (including “feelings of distress, anger or depression”) in comparison to the characteristics of TC CCAC SEC clients and caregivers not participating in the CSP
- Assess possible changes over time in key characteristics (including ability to continue to provide care) of caregivers who were TC CCAC clients, and who participated in the CSP at Time 1 (December, 2011) and Time 2 (January, 2013).

A first cut of TC CCAC RAI-HC data was received in December, 2011 (Time 1) including data for 89 TC CCAC clients participating in the CSP, as well as for 1554 clients in the TC CCAC SEC program. Because CSP participants were drawn from the SEC program, which provides intensive care management and enhanced home care services, but not additional caregiver supports, the SEC group offered a natural “control” for our analysis.

The Time 1 data cut also included hospital Emergency Department (ED) Notification data for CSP and SEC clients; ED Notification data count numbers of hospital ED visits over the previous six months. However, they are available only for clients over 80 years of age.

A second TC CCAC data cut was received in January, 2013 (Time 2). This cut contained the most recent RAI-HC assessment and ED utilization data for the panel of 89 TC CCAC home care clients enrolled at Time 1. Note that at Time 2, 33 of the original 89 panel members (about 35%) were no longer active in the project -- they had died, entered into LTC, or were no longer TC CCAC clients. Note also, that although the Time 1 and Time 2 data cuts were generated about a year apart, initial and subsequent RAI-HC assessments might have been conducted at different points, with some initial assessments completed even before the CSP began; this cautions interpretation of the results.

By Time 2, a new wave of caregivers was being enrolled into the CSP by seven community support service agencies (CSSA). These new participants received initial assessments using the RAI-CHA (Resident Assessment Instrument – Community Health Assessment), a version of the RAI-HC adapted for use by community agencies. However, these assessment data were not available within the time frame of the evaluation, so that CSSA clients could not be included in our RAI analysis.

2.2.5 Care Coordinators’ Debriefing Sessions

As noted, TC CCAC care coordinators played a lead role at the CSP start-up; they identified “at risk” caregivers of high needs older persons who were TC CCAC SEC clients. SEC care coordinators who engaged in the CSP also attended a day-long workshop provided by Dr. Joel Sadavoy and his team at the Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital, which informed them about the project and trained them to engage informal caregivers in a process of problem identification and problem solving.

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Care coordinators from 7 CSSAs serving diverse communities joined the project in its second year.

We “de-briefed” groups of TC CCAC and CSSA care coordinators to record their qualitative experiences, observations, and insights. While we had aimed to de-brief all care coordinators at regular three month intervals, their busy work schedules allowed fewer sessions.

De-briefing sessions averaged 90 minutes in length. To encourage open discussion, supervisors and managers were asked not to attend. To reassure care coordinators that their comments would not be attributed, evaluation team members did not audio-record sessions; however, at least two evaluation team members took detailed field notes at each session, and then cross-checked notes during analysis.

A first round of three de-briefing sessions with TC CCAC care coordinators was conducted soon after the project’s start-up, on October 31st, December 14th and December 22nd, 2011; a total of 25 care coordinators attended. We asked about:

- Caregiver selection -- how they determined which caregivers to select
- Basket of services – how the mix of supports provided to caregivers was determined
- Key challenges to date
- Key opportunities moving forward
- Overall assessment of the project.

A second round of two debriefing sessions, with a total of 16 TC CCAC care coordinators, took place on June 14th and November 5th, 2012. In these follow-up sessions we asked about:

- Changes in how care coordinators and caregivers negotiated support packages
- The impact of the CSP on caregivers, care recipients, care coordinators and the health care system.

We conducted an additional debriefing session with six CSSA care coordinators on October 9th, 2012. Since this was their initial de-briefing, we repeated first round questions asking about:

- Caregiver selection -- how they determined which caregivers to select
- Basket of services – how the mix of supports provided to caregivers was determined
- Key challenges to date
- Key opportunities moving forward
- Overall assessment of the project.

3.0 Findings

3.1 Context

Our environmental scan aimed to identify key characteristics of the context for the CSP; highlight external factors impacting on implementation and outcomes; and assess the extent to which the CSP aligned with key policy initiatives and directions (Rajnovich, et al., 2005).

There is growing interest in informal caregivers. The research and policy literatures reveal increasing attention to informal and mostly unpaid caregivers across the industrialized world (Neuman, et al., 2007; OECD, 2010).

Such interest is driven by genuine concern for the welfare and dignity of caregivers and the often vulnerable people they care for.

It is also driven by tough demographic and economic imperatives. As Ontario's *Action Plan for Seniors* (2013) emphasizes, more people are living longer, often with multiple chronic health and social needs; as a result, health care utilization and expenditures are expected to rise, putting additional strain on already stretched health care systems, and threatening sustainability.

Informal caregivers play a pivotal role. Although estimates vary, there is general agreement that informal caregivers – family, friends and neighbors – provide the bulk (70 to 90%) of the care required by older persons to keep them independent (OECD, 2010; CIHI, 2010). Not only do informal caregivers provide a range of instrumental and emotional supports, they are often the main interface with the formal care system, accessing and coordinating services on behalf of older persons who cannot manage on their own.

The caregiver role is increasingly important. Not only are more older persons living longer with multiple complex needs, they are less likely to be cared for in hospitals or residential LTC, particularly given the increasing policy emphasis on quicker hospital discharges, and persistent waitlists for residential LTC. While “aging at home” strategies respond to many seniors’ desire to live at home as independently as possible for as long as possible, they may also shift a greater burden of care onto informal caregivers (Health Council of Canada, 2012). Unpaid informal caregivers are thus increasingly providing care which previously would have been provided by paid professionals in well-resourced institutional settings.

A recent report by the Conference Board of Canada (2012) neatly summarizes this trend:

“Defined in its broadest sense, most home and community care is provided by family, friends, and volunteers. Our estimate of the contribution of this care is substantial—1.5 billion hours of unpaid home care support per year. This is between 8 and 11 times larger than the number of paid hours of care offered for home health, home support, and community care (estimated at between 140 million and 182 million hours). A

further shift toward care in the home and out of institutions ... means an even greater reliance on unpaid caregivers”.

Informal caregiving is in decline. While an estimated one in 10 adults across the industrialized nations is involved in informal caregiving, both the number of informal carers and the volume of care provided appear to be decreasing (OECD, 2011; Rajnovich, 2005). Demographic factors play a role. Smaller family size, increased childlessness and growing female labor market participation impact on caregiving (Rajnovich, 2005).

However, public policies may also contribute by failing to provide informal caregivers with adequate formal supports to sustain their role (Hollander, 2004).

There is an expanding range of caregiver support initiatives. Policy-makers across the industrialized world are implementing a growing range of caregiver support initiatives (Karp, et al., 2010). In Australia, for example, the National Respite for Carers Program gives caregivers a break from caring by coordinating access to respite services at the local level and by arranging 24 hour emergency respite care. The United Kingdom’s Carers Equal Opportunities Act (2004) provides carers with employment opportunities, extended benefits, and additional assistance so they can continue to provide unpaid care. Germany’s Social Long-Term Care Insurance provides benefits to individuals with low incomes by paying for time taken off work to perform caregiving duties, as well as respite for the duration that an informal caregiver is absent from caring. New Zealand’s Domestic Purposes Benefit supports full-time informal caregivers in the form of weekly payments.

Closer to home, the *Canadian Caregiver Coalition* lists a range of caregiver supports provided by federal/ provincial/territorial governments. These include direct caregiver benefits through the federal Veterans Independence Program (VIP) and the First nations and Inuit Home and Community Care Program, tax credits, caregiver allowances, respite, home help, and information and counseling (Hollander, 2004; Morton, 2010; Karp, et al., 2010). As part of its recently released *Action Plan for Seniors* (2013), Ontario promised to re-introduce legislation that will give employees up to 8 weeks of unpaid work leave to care for a family member with a serious medical condition.

Ontario’s *Seniors Strategy* (2013) also recognizes the need to provide some (albeit unspecified) level of support to informal caregivers. It observes that:

“we need to do more to support caregivers across our province, especially when their presence is the reason why so many older Ontarians have been – and will remain – able to age in their places of choice for as long as possible. ... All Ontarians stand to benefit when caregivers can be supported with information and access to a range of supports which will allow them to continue assisting those they care about” (p. 15).

The *Seniors Strategy* goes on to recommend caregiver support initiatives to:

- Improve awareness of services and supports available to unpaid caregivers with improved single points of access
- Promote awareness and uptake of current programs (for example, financial benefits and tax credits supporting the financial burdens of unpaid caregiving)
- Encourage the standardization of services and supports offered through the Alzheimer Society's First Link program and spreading this program to every LHIN across Ontario.

There is relatively little hard intelligence to guide the design and implementation of caregiver support initiatives. While documenting a range of approaches within and across jurisdictions, there is little systematic evaluation of which approaches work best for which caregivers (and cared-for persons) in what contexts.

For example, respite and self-managed care are among the most common support approaches in Ontario; however, eligibility and levels of benefits vary widely. For example, while some programs employ holistic assessments of caregiver needs, others appear to focus more on the needs of cared-for older persons while different programs offer varying levels of support. Moreover, systematic evaluations of caregiver support initiatives are uncommon and those that have been done (e.g., the Wesway Family Directed Respite Program, the SMILE Program, and VIP) do not provide conclusive evidence of cost-effectiveness even though they do consistently demonstrate high levels of satisfaction among participants.

The CSP is strongly aligned with key policy priorities and directions in Ontario. These include:

- *Ontario's ER/ALC Strategy*. This policy thrust looks to ways, including increased reliance on community-based care, to reduce the number of inappropriate hospital Emergency Room visits and persistent high numbers of Alternate Level of Care (ALC) hospital beds, beds occupied by individuals no longer requiring acute care but who cannot be discharged because of a lack of community-based care alternatives. The persistence of this problem is indicated by Ontario Hospital Association data (November, 2012) which show that in September 2012, over 17% of acute care hospital beds in the province were deemed ALC, a drop of just 1% from November, 2007.
- *Ontario's Aging at Home Strategy (2007)*. This four year, \$1.1 billion initiative aimed to maintain older persons at home longer through the provision of a broad array of non-clinical community-based supports (e.g., meals, transportation, friendly visiting, and adult day programs). While Aging at Home money was subsequently re-directed toward discharging older persons more quickly out of hospitals, it nevertheless reinforced a growing policy emphasis on home as the primary site of care for older persons.
- *Walker Report (2011)*. Commissioned by the Ministry of Health and Long-Term Care, *Caring for Our Aging Population and Addressing Alternative Level of Care* argued that a lack of community-based care alternatives in Ontario meant that hospitals and

“permanent” placement for seniors in residential LTC are too often costly and inappropriate “default” options. Walker concluded that a “fundamental system redesign” was needed to shift resources, as well as policy emphasis, to home and community.

- *Drummond Report (2012)*. The wide-ranging report of the *Commission on the Reform of Ontario’s Public Services* observed that rising health care costs threaten health system sustainability; that the health care “system” is not a system but a collection of disjointed services working in many silos;” and that, as a result of not being able to access appropriate, coordinated care, people with complex needs are constantly admitted and readmitted to hospitals driving up system costs. Drummond argued for a shift in policy emphasis from acute to chronic care and health promotion within a coordinated continuum including home and community care; and special attention to high needs, high cost users.
- *Ontario’s Action Plan for Health Care (2012)*. This document emphasizes the province’s commitment to ensuring that individuals are able to remain at home as long as possible. In particular, it points to system restructuring aimed at better meeting the needs of “today’s population, with more focus on seniors and chronic disease management.”
- *Ontario’s Seniors Strategy (2013)* and *Ontario’s Action Plan for Seniors (2013)* both emphasize that demographic imperatives (population aging and the rise of chronic illness) and fiscal imperatives (rising health care costs and the challenge of sustainability) require greater attention to coordinated, cost-effective care for older persons, particularly those with multiple, complex needs who are or who may become high health care utilizers. While the *Action Plan for Seniors* provides a review of previous government actions in support of seniors, the *Seniors Strategy* makes recommendations for future actions including more health promotion and home-based care and it acknowledges the crucial role of informal caregivers. It recommends, for example, the spread of *First Link* programs across Ontario to facilitate quick referral of persons with dementia and their caregivers to appropriate community-based counselling and support.
- *Health Links (2013)*. Ontario plans to implement 79 Health Links across the province to encourage greater collaboration between primary care, specialist care, hospitals, long-term care, rehabilitation, home care and community supports. By starting with the highest cost users -- the 1% to 5% who account for 66% of health care spending -- and developing local approaches to providing “the right care, at the right time, and in the right place,” Health Links aim to overcome system fragmentation, moderate system costs by avoiding unnecessary hospital visits, push new investments in primary health care, and make the leap from provider-centred to person-centred care. Health Links

anticipates greater interaction between local health providers to manage individuals with the greatest needs “in partnership with family and community.”

How does the CSP align?

- The CSP targets at risk caregivers and high needs older persons at the verge of hospital or institutional care. All older persons enrolled in the project are eligible for residential LTC; all caregivers are deemed “at risk” of burnout. By providing a basic level of support the CSP seeks to maintain caregiver resilience and capacity, thus reducing the likelihood of costly “default” to costly hospital and institutional care.
- By supporting caregivers, the CSP maintains community-based capacity to support an aging population. It recognizes that as more care needs are addressed outside of hospital and institutional settings, provided by unpaid and usually untrained family, friends and neighbors who are often not well equipped to sustain intensive care over extended periods.
- The CSP builds stronger linkages and collaboration between providers, thus contributing to greater system coordination and integration at the local level. In addition to providing direct support to individual caregivers, the CSP establishes a nexus for a growing collaboration of providers including the TC CCAC, community support agencies, and the Alzheimer Society.
- The CSP puts a powerful new “tool” in the hands of care coordinators. In addition to providing direct supports to caregivers, who are not typically recognized as home care “clients,” the CSP assists in engaging caregivers, building trust, and jointly identifying and solving problems, recognizing that if caregivers fail, high needs older persons are much more likely to default to the formal care system. The CSP thus solidifies a partnership between informal caregivers and formal care coordinators which can address immediate crisis, and build longer-term resilience and capacity.

3.2 Caregiver Characteristics

As indicated, caregivers were selected for the CSP on the basis of criteria including:

- Caregiver consent
- Caregiver willingness to use CSP funds as agreed
- Age – with some exceptions, caregivers and cared-for older persons had to be 55 years of age or older
- Caregivers were “primary” caregivers providing more than 10 hours per week qualified
- Care recipient and caregiver lived in the TC LHIN
- Care recipient and/or caregiver were considered to be “at risk”.

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The numbers in Table 1 are from CSP administrative data. They describe key characteristics of the panel of 89 caregivers enrolled at the beginning of the CSP project in late 2011, as well as the characteristics of all 258 caregivers enrolled in the CSP project at some point.

Table 1. CSP Caregiver Characteristics					
Characteristics	Label	Panel		All Caregivers	
		N	% (mean)	N	% (mean)
Age		89	(69.3 years)	258	(65.8 years)
Sex	Male	23	25.8%	59	22.9%
	Female	66	74.2	199	77.1
Language	English	59	66.3%	182	70.5%
	Other	30	33.7	76	29.5
Ethnicity	Caucasian	45	50.6%	137	53.1%
	Other	44	49.4	121	46.9
Observed Financial Need	Yes	87	97.8%	249	96.5%
	No	2	2.2	9	3.5
N of Cases		89		258	

The data for “all caregivers” (including the panel of 89 individuals) show that the majority faced, or were likely to face, challenges related to age, sex, language, ethnicity and financial capacity.

- Caregivers were often older persons themselves, averaging 65.8 years of age
- Over three quarters (77.1%) were female
- About a third (29.5%) spoke a language other than English
- Almost half (46.9%) identified with minority communities
- Virtually all (96.5%) were judged by TC CCAC care managers to be in financial need.

While differences are not marked, “panel” members (those enrolled at the beginning of the project) were somewhat older (averaging 69.3 years); more likely to be male; less likely to speak English; more likely to have roots in minority communities; and more likely to be judged to be in financial need.

3.3 Caregivers and Cared-For Older Persons

We used TC CCAC RAI-HC data to compare the characteristics of 1,554 SEC clients with those of 89 CSP clients enrolled at the beginning of the project (Time 1 -- December 2011); the results are presented in Table 2. Note that these data are for cared-for older persons, not for caregivers. The X^2 p-value in the right-most column indicates whether or not there are statistically significant differences between SEC and the CSP clients; differences identified with an asterisk (*) are significant at .05 or less which means that there is less than a 5% probability they occurred by chance.

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Table 2. Characteristics of SEC and CSP Clients (Older Persons), Time 1 (Dec. 2011)						
		SEC Time 1		CSP Time 1		X² p-Value
Characteristics	Label	N	%	N	%	
About the Senior						
Age	≤60	3	0.2	2	2.2	0.000*
	61 - 79	372	23.9	39	42.9	
	≥80	1179	75.9	50	54.9	
Language	English	880	56.6	39	42.9	0.010*
	Other	674	43.4	52	57.1	
Maple Level	Low	18	1.1	0	0	0.000*
	Mild	16	1.0	0	0	
	Moderate	511	32.9	20	22.5	
	High	626	40.2	36	40.4	
	Very High	383	24.6	33	37.1	
IADL Difficulty Scale	No Difficulty	4	0.3	0	0.0	0.001*
	Some Difficulty	5	0.3	0	0.0	
	Some Difficulty	26	1.7	0	0.0	
	Some Difficulty	11	0.7	0	0.0	
	Great Difficulty	112	7.2	1	1.1	
	Great Difficulty	705	45.4	26	29.2	
	Great Difficulty	691	44.5	62	69.7	
ADL Hierarchy Scale	Independent	275	17.7	7	7.9	0.000*
	Some Assistance	689	44.3	28	31.5	
	Dependence	590	38.0	54	60.7	
Cognitive Performance Scale¹	Borderline Intact	156	10.0	6	6.8	0.000*
	Mild Impairment	684	44.0	28	31.8	
	Severe Impairment	583	37.5	54	61.4	
Verbally Abusive Behaviour	No	1439	92.6	76	85.4	0.014*
	Yes	115	7.4	13	14.6	
Physically Abusive Behaviour	No	1522	97.9	83	93.3	0.004*
	Yes	32	2.1	6	6.7	
N of Cases (¹missing data)		1554		89		

The data in Table 2 show that CSP clients had high needs even in comparison to SEC clients, who themselves are among the highest needs clients served by the TC CCAC; all are eligible for residential LTC.

Compared to SEC clients, CSP clients were:

- **Less likely to speak English:** 57.1% of the CSP clients compared to 43.4% of SEC clients spoke a language other than English
- **More likely to record high MAPLe (Method for Assigning Priority Levels) scores:** 37.1% of CSP versus 24.6% of SEC clients scored “very high” on the MAPLe, an index of need widely used to determine eligibility for enhanced home care services and residential LTC
- **More likely to experience great difficulty with IADLs (instrumental activities of daily living):** 69.7% of CSP clients versus 44.5% of SEC clients had high IADL Difficulty Scale scores, indicating that they were highly dependent on others to perform such activities as meal preparation, housekeeping, phone use, medication management
- **More likely to be dependent on others to perform ADLs (activities of daily living)** 60.7% of CSP clients versus 38.0% of SEC clients could not perform such ADLs such as eating, personal hygiene, locomotion, toilet use on their own
- **More likely to have cognitive difficulties:** 61.4 % of the CSP clients versus 37.5% of SEC clients scored in the severe impairment range of the Cognitive Performance Scale
- **More likely to demonstrate disruptive or aggressive behaviors:** 14.6% of CSP clients (versus 7.4% of SEC clients) were verbally abusive; 6.7% of CSP clients (versus 2.1% of SEC clients) were physically abusive.

The data in Table 3 report key characteristics of the panel of 89 cared-for older persons in the CSP at Time 1 compared to the 56 who remained in the CSP at Time 2 (about one year later). The X² p-values in the right-most column indicate whether or not there are meaningful differences between Time 1 and Time 2; values less than or equal to 0.05 indicate statistically significant change.

These data show that while assessment measures tend to “worsen” over time (e.g., a greater proportion of clients are categorized as “dependent” by virtue of their ADL Hierarchy scale scores), the effects are not statistically significant.

Table 3. Characteristics of CSP Clients (Older Persons), Time 1 (Dec. 2011) and Time 2 (Jan. 2013)						
		CSP Time 1		CSP Time 2		X² p-Value
Characteristics	Label	N	%	N	%	
About the Senior						
Maple Level	Low	0	0	0	0	.095
	Mild	0	0	0	0	
	Moderate	20	22.5	11	19.6	
	High	36	40.4	26	46.4	
	Very High	33	37.1	19	33.9	
IADL Difficulty Scale	No Difficulty	0	0	0	0	.999
	Some Difficulty	0	0	0	0	
	Great Difficulty	89	100	56	100	
ADL Hierarchy Scale	Independent	7	7.9	3	5.4	.203
	Some Assistance	28	31.5	12	21.4	
	Dependence	54	60.7	41	73.2	
Cognitive Performance Scale	Borderline Intact	6	6.7	5	8.9	.987
	Mild Impairment	28	31.5	16	28.6	
	Severe Impairment	54	60.7	35	62.5	
Verbally Abusive Behaviour	Yes	13	14.6	4	7.1	.097
	No	76	85.4	52	92.9	
Physically Abusive Behaviour	Yes	6	6.7	2	3.5	.936
	No	83	93.3	54	94.7	
N of Cases		89		56		

These data show that while those remaining in the CSP tended to have relatively stable characteristics and needs, a substantial number had dropped out due to factors such as death, admission to long-term care, or migration out of the TC CCAC catchment area. Of the original 89 older person/caregiver pairs enrolled in the CSP at Time 1, only 56 remained at Time 2; 33, or more than a third of the original participants, were no longer engaged.

Such attrition might be expected given that the CSP targets high needs, high risk caregivers and cared-for older persons; regardless of the merit of the CSP, older persons experiencing high needs continue to decline and eventually die.

We tested for change over time in two alternative ways:

- By considering only the 56 participants who were present at both Time 1 and Time 2

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- By including all 89 original participants at both points in time. This is consistent with guidelines regarding treatment of parallel groups during randomized trials (Moher, Hopewell, Schulz, Montori, Gotzsche, Devereaux, Elbourne, Egger & Altman, 2010), which dictate that all participants should be included in comparisons, regardless of whether or not they completed the study.

Because these alternative approaches also failed to demonstrate statistically significant differences, we have not reported them here. However, we emphasize that in spite of not being able to show statistical change in the characteristics of the panel, the panel nevertheless underwent a major change, since about a third of the original participants at Time 1 no longer participated at Time 2.

The data in Table 4 report formal and informal care characteristics for SEC and CSP clients at Time 1 (December, 2011).

Table 4. Formal and Informal Care for SEC and CSP Clients (Time 1, December 2011)						
Variable	Category	SEC Time 1		CSP Time 1		X ² p-Value
		N	%	N	%	
Caregiver Lives with Client	Yes	800	51.5	75	84.3	0.000*
	No	754	48.5	14	15.7	
Caregiver Relationship to Client¹	Child or Child-In-Law	891	58.3	38	42.7	0.000*
	Spouse	416	27.2	48	53.9	
	Other Relative	128	8.4	3	3.4	
	Friend/Neighbour	92	6.0	0	0.0	
Formal Home Care Hours¹	0	208	13.6	10	11.2	0.852
	1-25	1143	74.8	67	75.3	
	26-50	98	6.4	5	5.6	
	51-75	28	1.8	3	3.4	
	75-100	9	0.6	1	1.1	
	100+	42	2.7	3	3.4	
Extent of Informal Weekday Hours of Care¹	0	64	4.2	0	0.0	0.000*
	1-25	1091	71.7	44	49.4	
	26-50	277	18.2	27	30.3	
	51-75	46	3.0	13	14.6	
	75-100	30	2.0	4	4.5	
	100+	13	0.9	1	1.1	

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Extent of Informal Weekend Hours of Care¹	0	94	6.2	1	1.1	0.001*
	1-25	1366	89.8	77	86.5	
	26-50	60	3.9	11	12.4	
	51-75	0	0.0	0	0.0	
	75-100	0	0.0	0	0.0	
	100+	1	0.0	0	0.0	
Caregiver Willingness to Increase IADL Support¹	Willing	488	32.6	45	50.6	0.000*
	Not Willing	1009	67.4	44	49.4	
Caregiver Unable to Continue Caring	Yes	246	15.8	26	29.2	0.001*
	No	1308	84.2	63	70.8	
Caregiver Expresses Feelings of Distress, Anger or Depression	Yes	552	35.5	58	65.2	0.000*
	No	1002	64.5	31	34.8	
Caregiver Distressed	Yes	661	42.5	64	70.3	0.000*
	No	893	57.5	27	29.7	
N of Cases (¹missing data)		1554		89		

These data reveal a number of key differences and similarities:

- CSP clients were more likely than SEC clients to have their caregiver living with them (84.3% vs. 51.5%), and to have caregivers who were spouses (53.9% vs. 27.2%)
- While the assessed needs of CSP clients were higher there was no significant difference in hours of formal home care received. We note that no formal hours of care were recorded for a tenth of CSP and SEC clients (not precluding the possibility that they received formal care from sources other than the TC CCAC)
- While CSP and SEC clients had needs which were sufficiently high to qualify them for residential LTC with its 24/7 staffing and coverage, they continued to live at home with the equivalent of two shifts of formal care per week -- 17.8 hours for CSP clients, versus 16.5 hours for SEC clients
- Informal caregivers provided the bulk of the care required by these high needs older persons. Informal caregivers of CSP clients averaged 35 hours of care during the week and 15 hours on weekends (for a total of 50 hours per week); SEC informal caregivers averaged 21 and 9 hours of care during the week and weekends respectively (for a total of 30 hours). Unpaid informal care hours thus far outweighed paid formal care hours
- A majority of CSP caregivers were still willing to increase the amount of time they spend in caregiving activities: just over 70% indicated that they were willing to

increase the amount of time providing emotional support, and 50.6% stated their willingness to increase the amount of time they spend providing IADL support. This compares to 60.1% of caregivers in the SEC who were willing to increase time spent on emotional support, and 32.6% who were willing to increase the time spent on IADL support.

However, heavier informal care burden may come at a cost; caregivers in the CSP recorded higher levels of stress and burden. Compared to SEC caregivers, CSP caregivers were more likely to:

- State they were unable to continue caring (29.2% in the CSP versus 15.8% in the SEC program)
- Express feelings of distress, anger or depression (65.2% in the CSP versus 35.5% in the SEC program)
- Be classified as “distressed” on an composite index combining willingness to continue to care and feelings of distress; seven out of ten (70.3%) of CSP caregivers, compared to 42.5% of SEC participants, were distressed.

We compared Time 1/Time 2 measures of formal and informal care for the panel of 89 CSP participants enrolled at Time 1 using the three different methodological approaches described above. Once again, we failed to observe any significant differences and thus have not presented the results. However, it is worth noting that:

- CSP caregivers maintained an average of 50 hours of care per week
- Seven out of 10 CSP caregivers continued to experience distress.

We also compared the number of Emergency Department (ED) admissions among SEC and CSP clients over age 80 in the 6 month period April – September 2011 (prior to the initiation of the CSP).

The findings, presented in Table 5, show no significant difference between SEC and CSP participants; while CSP participants tended to have fewer visits, both groups averaged less than one admission over the previous 6 months. In fact, as shown by relatively large standard deviations, numbers of admissions varied substantially within both groups, with some individuals experiencing multiple admissions, and many, none at all.

	SEC		CSP		
Characteristic	Mean	Std. Dev	Mean	Std. Dev	p-value
Number of ED Admissions	0.87	1.771	0.40	.808	.060
N of Cases	1554		89		

We also aimed to compare numbers of ED admissions among SEC and CSP clients at Time 1 versus Time 2; however, resource constraints precluded such comparisons.

3.4 TC CCAC Care Coordinators' Debriefing Sessions

We conducted two waves of debriefing sessions with TC CCAC care coordinators participating in the CSP.

3.4.1 First Round Highlights

Results from our first wave of debriefing sessions (October to December, 2011) were presented in our Preliminary (January 2012) and Intern Reports (June 2012). In summary, we found that:

- **Care coordinators overwhelmingly approved of, and supported the CSP.** While they had many positive suggestions for improvement, all felt that the project recognized and addressed the needs of caregivers in their own right, many of whom faced overwhelming challenges on a day-to-day basis. It also allowed care coordinators to better manage challenging cases -- by providing caregiver supports, including counselling and care planning, they could reduce the number of anxious phone calls, engage in problem-solving, and avoid crisis.
- **When selecting caregivers for the CSP, care coordinators considered additional contextual factors.** These included:
 - Family support available to caregivers (in addition to support for cared-for older persons)
 - Presence of cultural/linguistic barriers
 - Caregiver risk of mental and physical health problems.
- **Care coordinators valued the CSP's flexibility.** Instead of having to work with standard services and units of care, care coordinators now had greater opportunity to think "out of the box" and to find out what was likely to make a real difference for caregivers, including unconventional options like yoga, exercise, massage or an evening out at the movies. Even the small amount of money available through the CSP allowed care coordinators to focus more on caregivers, to build trust and communication, and sustain caregiver capacity.
- **Care coordinators placed high value on the counselling aspect of the CSP.** While a cheque for \$1500 might provide some help with immediate crisis, the real benefit of the CSP was the opportunity the money created for professional care coordinators to engage in an ongoing "conversation" which better equipped caregivers to take control of their lives and avoid crisis over the longer term.
- **The CSP generated multiple, albeit, sometimes hard-to-quantify benefits.** Care coordinators noted that the CSP resulted in many qualitative improvements (e.g., quality of life, peace of mind and confidence in the future). It also helped to better anticipate and manage challenges. However, it might not be realistic to expect that

caregiver burden and stress would decrease measurably as a result of the CSP, since the needs of cared-for older persons would continue to increase as they aged, and since many had already “maxed out” formal services. Nevertheless, the CSP acknowledged and valued caregivers in their own right, and in doing so, increased their sense of value and self-worth, which helped them to continue to care. Outcomes to be measured in future evaluation should include:

- Maintenance of caregivers’ current abilities (or prevention of deterioration)
- Reduction in the number of crisis applications for long-term care
- Improvements in the social, emotional and physical status of the caregiver.

3.4.2 Second Round Themes

The second round of debriefing sessions with TC CCAC care coordinators (June 14th and November 5th, 2012) elaborated these themes.

- **Conversation is key.** Care coordinators confirmed that the CSP’s flexibility allowed them to talk through what was best for the caregiver. While the money bought some immediate improvements in caregivers’ lives, more enduring benefits stemmed from the process of jointly identifying problems and finding solutions. Knowing that their contributions were valued, and that they were not alone in meeting new challenges, caregivers were empowered to look ahead with greater confidence.
- **Conversation had shifted more toward the needs of caregivers.** At the beginning of the project, conversations often focused on the immediate needs of cared-for older persons; when care coordinators visited caregivers for the second time, conversations turned more readily to what caregivers themselves needed. Once caregivers got used to the idea of receiving help themselves, they were better able to articulate what they needed; they considered a broader array of “creative” services including wellness supports (e.g., gym memberships, massage) which would help them continue to care.
- **The CSP should be a standard component of care for all high needs older persons.** Care coordinators emphasized that while the CSP targeted caregivers who were already “at risk” and often at the point of crisis, it would be better to engage earlier. If caregivers knew they would be supported in their crucial role, more individuals might be willing to take on caregiving in the first place, and they would be better able to anticipate and respond to challenges which might otherwise prompt a hospital visit or a LTC admission. While the CSP had provided benefits to a needy few, it should become a standard component of care planning.
- **The CSP generated many real, albeit hard-to-measure benefits.** When asked if the CSP had reduced caregiver stress generally, care coordinators said that they thought this might have happened in a few cases. Most “at risk” caregivers, however, continued to experience stress as they cared for high needs older persons, and as they dealt with formal service constraints. For example, one care coordinator noted that because the

blood work was no longer covered in the home, caregivers now had to find ways of transporting cared-for older persons to doctors' offices or labs, which meant new costs and logistical challenges, creating stress.

- **The CSP had avoided some hospital visits and LTC placements.** For example, one older person had a dental emergency and another had a bad urinary tract infection; such events often resulted in hospitalization. Nevertheless, because of the enhanced supports available through the CSP, crisis had been averted. Because the CSP equipped caregivers to better anticipate and understand the challenges that they faced, crises were being avoided.
- **The CSP produced real costs savings.** For example, while families with limited means would often call emergency services to transport older persons to clinics or medical appointments (at considerable cost to them and the system), the CSP paid for more appropriate transportation. More substantial savings may be anticipated over the longer term as the CSP builds capacity to avoid unnecessary hospital and LTC use.
- **Care coordinators had benefitted.** Care coordinators unanimously endorsed their participation in the CSP. They felt good about being able to provide an immediate response to caregivers compared to the reality of long wait lists for other services, and service reductions. They stated that while engaging caregivers did initially increase workloads, it also made continuing workloads more manageable. The CSP allowed them to do their job better.

3.5 CSSA Care Coordinators' Debriefing Session

We debriefed CSSA care coordinators in October 2012. Recall that while initial waves of clients had been enrolled by TC CCAC SEC care coordinators, the project was subsequently broadened to include 7 CSSAs serving diverse cultural communities. We asked about caregiver selection, services, challenge, and the success of the project overall.

Much of what we had heard from the CSSA care coordinators echoed what we heard from their TC CCAC counterparts: most importantly, there was strong support for the CSP and the flexibility it offered to address caregiver needs on a proactive and continuous basis.

- **Caregiver selection.** CSSA care coordinators defined caregiver risk even more broadly than TC CCAC case managers. They noted that "high risk" caregivers may include those who are tired, fatigued, have minimal financial and social resources (including education and English language ability), or have "maxed out" available support services. They clarified that "risk" may have multiple sources including the needs of the cared-for older person; the resources and capacity of the caregiver; and access to needed formal services which may vary across communities. Moreover, risk has cultural dimensions: not only do some cultures expect more from caregivers, but they also tend to see

reliance on formal services as a defeat. While this means that older persons are able to live at home even at very high levels of need, there may be fewer options when crisis occurs, precipitating emergency department visits, and crisis referrals to long-term care; it is crucial to get to these caregivers earlier.

- **Basket of services.** When asked about the services most needed by caregivers, CSSA care coordinators highlighted respite and transportation. Yet, like TC CCAC care coordinators, they felt that the real strength of the CSP lay in the fact that a small dollar investment could be used to engage caregivers in an ongoing process of problem identification and problem solving, leading to longer term solutions. The CSP allowed caregivers to consider, often for the first time, what they needed to continue to care, not just what loved ones needed. It also gave care coordinators an opening to more accurately diagnose problems and help build creative solutions before crisis occurred.
- **Money alone is not sufficient.** When asked if giving caregivers a monthly allowance wouldn't be simpler, case managers emphasized that money might help to deal with immediate financial problems, the CSP's counselling and support functions built longer-term capacity. By themselves, many caregivers would not have the personal resources to get beyond immediate problems.
- **Caregivers needed to know that the CSP would continue.** Like TC CCAC care coordinators, CSSA care coordinators spoke highly of the administration of the CSP which in their view was very responsive, generated little additional administrative burden for them, and facilitated considerable flexibility in the use of funds. The real challenge had to do with the (then) time-limited nature of the project (at that point slated to run only until April 2013). What would happen when the funding ran out? Some care coordinators suggested that to achieve its full potential, the project would have to be ongoing, and would have to be seen by caregivers to be ongoing, so that caregivers saw the reason to engage in often difficult conversations. In fact, some care coordinators wondered whether such as small-scale programs was in itself a bit of a "band aid," since in aiming to build caregiver capacity and reduce stress, it deflected attention away from the fact that available home and community care was often not sufficient to meet needs.

3.6 Caregiver One Minute Evaluations

The evaluation team received anonymized responses from a total of 360 one-minute evaluations, including 216 evaluations administered at Time 1 (December, 2011) and 144 administered at Time 2 (January, 2013); many of these responses were brief or incomplete.

3.6.1 Satisfaction and Stress

Table 6 reports caregivers' self-reported levels of stress and overall satisfaction with the CSP.

Although caregivers were judged by care coordinators to experience high levels of stress, and although the RAI-HC data (see Table 4) showed that a majority of caregivers expressed feelings

of distress, anger or depression, levels of self-reported stress tended to be more moderate, averaging about the mid-point of the 10-point scale at Time 1 and Time 2. We note, however, that relatively few respondents rated their stress at Time 1 cautioning interpretation of this finding.

By comparison, satisfaction scores were high, averaging about 8.8 on the 10 point satisfaction scale at Time 1, and 9.1 at Time 2.

Table 6. Caregiver Stress and Satisfaction Levels						
Characteristics	Label	Time 1		Time 2		X ² p-Value
		N	Mean	N	Mean	
Stress	1= Not at all Stressed 10 = Very Stressed	92	5.8	145	5.8	.507
Satisfaction	1 = Very Dissatisfied 10 = Very Satisfied	203	8.8	145	9.1	.531

3.6.2 Most Important Issues for Caregivers

Responses to the question “What is the most important issue (or problem) you face as a caregiver,” highlighted three interrelated dimensions of caregiver burden and stress also noted by care coordinators:

- **Stress and burden related to the needs of the cared-for older person.** Informal caregivers provide the bulk of the care required to maintain older persons in their homes, often on a 24/7 basis, often with limited resources and assistance. Several caregivers wrote that the biggest challenge they faced was ‘not having enough time’ this generates stress and burden. Caregivers specifically noted the challenges associated with managing multiple medical conditions (e.g., dementia *and* diabetes) requiring multiple medications and providers; behavioural issues (i.e., aggressive or abusive behaviours) which some confront on a daily basis, often without help because formal care providers will refuse to provide service; and transfers and transitions (e.g., between providers, or from hospital to home) which can generate considerable stress.
- **Stress and burden related to caregiver characteristics and capacity.** Caregiving, particularly for high needs older persons, is demanding. However, caregivers do not start on an equal footing. For example, lack of financial resources can generate stress as caregivers scramble to pay the costs of supplies (e.g., sanitary products and nutritional supplements), user fees and co-payments; they may have to make hard choices about

where they can scrimp, often choosing to short themselves rather than the person they care for. Such choices are no less difficult for a working spouse who has to give up paid employment to care for a family member, or who has to choose between giving care to an older person, or to younger family members. Caregiver capacity is impacted by factors including finances, mental and physical health, isolation, language and culture.

- **Stress and burden related to challenges accessing formal services.** Caregivers commented that formal services and supports were often difficult to access, or insufficient. Not knowing what to do, and feeling that they had to take on the burden of care by themselves, created anxiety and stress. Service caps, tight eligibility requirements, and service reductions, made caregivers feel powerless and unable to continue to provide care. Even when they connected with formal services, they had to manage multiple services and providers in the home, they had to be ready to cover when formal providers did not turn up, and they had to transport older persons to medical appointments and services at different locations outside the home. The burden and uncertainty this caused made them want to give up.

3.6.3 What Caregivers Said They Need

Caregivers who responded to the question “what help or assistance would you need to continue caregiving?” consistently identified “more support” as their greatest need. Three main categories of supports emerged:

- Education and counselling, including training to acquire specific skills (e.g., how to manage a transfer or care for an older person with dementia)
- Support services like transportation, housekeeping and respite
- Funding to purchase extra care and/or supplies for cared-for older persons.

3.6.4 How Well the CSP Responds

When asked “How well is the caregiver project for seniors helping to meet your needs?” caregiver responses were overwhelmingly positive. Words like “helpful” and “thankful” were used to describe the CSP. Caregivers acknowledged the project’s contributions in key areas:

- **Finances.** By alleviating some of the costs of caregiving (e.g., for services, supplies and equipment), the CSP contributed to the financial stability of the caregiver and cared-for person. Some caregivers mentioned that they benefited significantly from the financial component as it allowed them to purchase much needed equipment; others highlighted how having funds to pay for extra help made them feel emotionally supported
- **Time for themselves.** The CSP made a “huge difference” by allowing caregivers to engage in social activities, take part in everyday events, go shopping, run errands, and care for their own health
- **Time for others.** The CSP allowed caregivers greater opportunity to reconnect with other family and friends, relieving isolation, strengthening relationships, building morale

and increasing self-worth

- **Control over their own lives.** The CSP offered caregivers greater control over their own lives; they could now anticipate and plan for the future.

Among typical comments:

- “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 continue to take care of their loved ones”
- “[I] couldn’t manage without it”.

Thirty one respondents said that the CSP did ‘not fully’ meet their needs. However, for the most part, such reservations did not arise from weaknesses in the project; rather they reflected anxiety that the project was time-limited and would end, returning them back to difficult situations because ‘extra support’ would no longer be available. For example, one caregiver mentioned

- “It does help but I am elderly myself and don’t have strength.... This grant has helped but still only for a short time”.

3.6.5 Most and Least Liked Aspects of the CSP

Caregivers were asked:

- What do you like most about the caregiver support project for seniors?
- “What do you like least about the caregiver support project?”

A total of thirty-two caregivers explicitly stated that they felt the CSP should be continued.

They identified a range of positive features including:

- Administration was simple (few forms and red tape)
- Financial assistance allowed them to pay for help
- Having access to needed supports gave them “a so deserved break”.
- The project gave them “peace of mind”
- Knowing that their loved ones were being cared for allowed them to go out to work or run errands
- Someone to rely on
- Extra care
- While financial aid was important, the care coordinator’s “compassion, understanding in dealing with the real world and situations of the elderly and caregiver as well” was highly valued.

Least liked aspects of the program included:

- Filling out forms
- Obtaining receipts

As noted above, the most frequently mentioned concern was that the program would terminate. Caregivers stated:

- “I have no criticism of the project except I would like to see many more projects and financial help”
- “The fact that it is not ongoing. It only lasts a short time”
- “What I like least is that this is coming to an end- I wish it could continue.”

3.6.6 What Caregivers Would Change

Caregivers who responded to the question “What, if anything would you change about the caregiver project for seniors?” were consistently positive:

- 53 caregivers stated that they would change “nothing” or would want “more of a good thing”
- About the same number (50) hoped that the project would continue
- 18 caregivers stated that they would have liked more information about the project, including information on how the money could be spent; some suggested an information sheet clearly outlining the goals of the project and expectations of the caregivers (i.e. reporting guidelines).
- One caregiver mentioned that the initial feedback form was sent too early as they had not experienced enough of the CSP to provide thoughtful responses.

Negative feedback was rare and not specific to the CSP; rather, a few caregivers voiced concerns about the challenges they experienced accessing needed formal care. For example, one respondent indicated that they would like to have PSW support over night; another felt that the CCAC should provide them with more PSW hours.

3.7 Administrative Overhead

In addition to the direct costs of providing supports and services to caregivers, the CSP logged substantial additional costs associated with start-up and ongoing administration; these are detailed in a “briefing note on administrative overhead” written by the CSP Coordinator (see Appendix C).

This note confirms what we heard from caregivers and other key informants that the relatively modest dollar amounts provided to care coordinators (averaging about \$1500 per caregiver per year), established a platform for engaging caregivers in a highly constructive and dynamic process of problem identification and problem solving which in itself, helped to build capacity and relieve stress.

However, the CSP Coordinator’s briefing note reminds us that training care coordinators, and then procuring and accounting for individualized services and supports takes time and effort, especially during start-up.

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For example, the briefing note reports that the initial round of training for care coordinators cost just under \$40,000. Of course, this investment is likely to generate continuing dividends as care coordinators are better equipped to manage not only the needs of CSP clients, but other clients as well.

Ongoing project administration was considerably more costly. The briefing note documents the high administrative effort required to track scores of individual invoices for individual caregivers. It gives a high end example of 96 separate invoices for goods and services submitted by just one caregiver during a 12 month period, with each invoice requiring processing and sign-off by the Coordinator, and then the finance department, for reimbursement. While the costs of administration were absorbed by AST as a pro bono contribution to the CSP, they were substantial; the briefing note estimates a “total administrative cost including salary and expenses” of \$141,500 annually.

This does not suggest that the CSP is a poor investment; in fact, the Project Manager’s note identifies a range of positive outcomes. However, it does suggest attention to ways of streamlining administration and reducing unnecessary paperwork; a “pre-payment” strategy is suggested. This note also suggests that costs should be weighed against a range of benefits for caregivers and cared-for persons, care coordinators, and system.

4.0 Conclusions

Although simple in concept, our evaluation emphasizes that the CSP is a complex intervention encompassing multiple stakeholders and outcomes over short and longer-terms. The following composite vignette, based on actual CSP participants, demonstrates key dimensions of this complexity. It also shows, on a personal level, the formidable challenges that may be faced by caregivers as they work to keep their loved ones at home.

Julia

Julia, an 82 year old woman, provides around-the-clock care for her 85 year old husband who was diagnosed with colorectal cancer 8 years ago and more recently started developing symptoms of Parkinson's disease.

Providing care is a full-time job. Julia wakes every morning at 5 AM to groom and dress her husband, change his colostomy bag, and wash and replace his incontinence brief. She then prepares a special breakfast that requires her to blend his food and mix in his medications. Julia feeds this meal to her husband four times daily. In the evening Julia repeats her morning routine. Since her husband does not like receiving care from others, Julia has little time to care for herself. Her only respite comes from two daily visits from a personal support worker.

As part of the CSP, Julia and Dorothy (her care coordinator) worked together to identify and address challenges. Dorothy and Julia determined that Julia required time away from her caregiving duties to attend to her own health needs and to spend time with other family members. Dorothy and Julia agreed that they would use funds from the CSP to hire a family friend to provide respite since this friend spoke the family's primary language, and Julia knew that this person was reliable and that her husband would accept her care. Ongoing conversation also revealed that Julia was becoming increasingly distressed about the costs of providing care for her husband. Using the CSP funds, Dorothy and Julia determined it would be helpful to have medical supplies paid for and delivered to Julia's home. Finally, it was determined that Julia needed to take better care of her diabetes; the balance of the CSP funds were used to purchase a gym membership and consultations with a nutritionist to help Julia get back on track.

Julia represents a growing number of informal caregivers, many of whom are themselves aging, who provide essential emotional, personal, instrumental and medical care to aging family members, allowing them to continue to live in their own homes as independently as possible, for as long as possible, thus also reducing demand for costly hospital and institutional care.

But, as the vignette shows, caregiving comes at a cost. Julia, and many others like her, can work long hours, often ignore their own needs, become increasingly isolated from family and friends, and push themselves to the brink of burnout. Nevertheless, there have been few

resources to support Julia, increasing the likelihood that both she and her husband will “default” to institutional care.

The CSP directly addresses this need. Using a relatively modest dollar investment, it equips care coordinators to engage “at risk” caregivers of high needs older persons in a process of problem-identification and problem-solving, aiming not only to manage immediate crisis but to build longer-term resilience and capacity. In doing so it pushes beyond conventional thinking and action. For example:

- The CSP expands definitions of the “unit of care” to include the informal caregiver as well as the cared-for older person
- The CSP transforms the “basket of services” from a fixed list of services offered by providers, to combinations of services and supports which best serve the needs of caregivers and cared-for older persons
- The CSP redefines the relationship between formal and informal care, with informal caregivers becoming active participants in decision-making.

In doing so, the CSP is strongly aligned with key research and policy directions. The CSP:

- Formally recognizes the crucial role of caregivers who provide the bulk of the care for community-dwelling older persons as “clients” in their own right
- Focuses on at risk caregivers and high needs older persons who are, or who could become, high health care utilizers; the RAI-HC data confirm that CSP participants had higher needs even than SEC clients who themselves are LTC eligible
- Builds community-based capacity by equipping caregivers and care coordinators to mitigate short-term crisis, and sustain informal caregiving
- Strengthens linkages between providers, thus contributing to greater system integration.

We observed strong support for the CSP among participants. For example,

- Care coordinators overwhelmingly approved of, and supported the CSP. They valued its flexibility, the opportunity it gave them to engage caregivers and find out what would make a real difference for them and cared-for persons, over short and longer terms. Care coordinators felt that the CSP generated a range of benefits including improved crisis avoidance and maintenance of caregiver capacity. They felt that the CSP should be a standard component of care for all high needs older persons, and that it should be expanded to engage caregivers before crisis occurs.
- Caregivers reported that as a result of the CSP, they were better able to carry the financial and personal burden of caregiving; they had more time for themselves, were able to reconnect with family and friends, and had more control over their lives. They

appreciated the fact that program administration was simple, and that they had someone to rely on. They expressed high levels of satisfaction with the CSP; their main concern was that it would end.

The evaluation results also clarify that while caregiver stress and burden are often presented as a function of the needs of cared-for persons, these stem from other sources as well including:

- **Caregiver characteristics and capacity.** “High risk” caregivers may include those who are tired, fatigued, have minimal financial or social resources (including education and English language facility), or have “maxed out” available support services
- **Access to needed formal supports.** Accessing needed formal supports, even when they are available, can be a source of stress. Finding the right services and then negotiating eligibility requirements and service restrictions, can make caregivers feel powerless and unable to continue to provide care. Caregivers and care coordinators both mentioned that ongoing service “cuts” can push caregivers closer to burnout.

These points seem crucial. Caregivers are not a homogeneous group; they bring with them widely varying resources including income, education, language and literacy skills, as well as personal health and functional capacity, which make them more or less capable of responding, on a continuing basis, to the needs of older persons as they age and decline. CSSA coordinators, in particular, emphasized that more could be done, earlier on, to build, or at least maintain capacity, so as to avoid crisis.

As importantly, our environmental scan emphasizes that the CSP takes place in a period of rising demand but “no new money.” One consequence is that existing home and community care resources are stretched further. According to care coordinators, this has meant fewer resources available even to high needs older persons and caregivers before crisis occurs; they cited examples of service reductions including fewer PSW hours and the termination of coverage for diagnostic tests done in the home. Our own analysis of RAI-HC assessment data shows that past a certain point, increased hours of informal care are not matched by increased hours of formal care. Coupled with constraints on other publicly-funded programs, the real test is not whether the CSP reduces caregiver stress and burden in the short run, but whether it equips caregivers to persist longer.

It was not possible, within the constraints of this formative evaluation, to offer definitive answers to these key questions. However, caregivers and care coordinators, as well as CSP staff, concluded that the CSP did build longer-term capacity, that it was a good investment for people and system, and that it should, therefore, be sustained and scaled-up.

5.0 Recommendations

Recommendation 5.1. Sustain, scale-up and spread the success of the CSP. The CSP is strongly supported by caregivers, care coordinators and CSP staff who see it as a valuable and ground-breaking initiative. In addition to managing immediate crisis and improving the quality of life of caregivers and cared-for older persons in the short term, the CSP builds more lasting caregiver capacity which can help avoid future crisis resulting in hospitalization or institutionalization.

Recommendation 5.2. Broaden inclusion criteria to reach caregivers before crisis occurs. Targeting caregivers earlier before they are “at risk” can increase opportunity to avoid as well as manage crisis. While the modest dollars provided by the CSP helped to address immediate problems, the real and more lasting value was that the money became a catalyst for engaging informal caregivers in a continuing process of problem identification and shared decision-making which in and of itself, relieved stress. The ability to anticipate challenges and co-create solutions has clear benefits at individual, organization and system levels. A more expansive set of eligibility criteria facilitating earlier intervention is desirable.

Recommendation 5.3. Recognize the caregiver as an essential part of the “unit of care” in home and community. While episodic curative care identifies the individual “patient” as the “unit of care” apart from their social context, the research and policy literatures increasingly emphasize that in home and community, informal caregivers are crucial. Not only do caregivers provide a range of direct emotional, instrumental and medical supports, they are often the interface with the formal care system, accessing and managing formal services for those who cannot manage on their own. Indeed, as care coordinators observed, without the ongoing support of caregivers, many older persons with complex needs, including growing numbers with Alzheimer’s disease and other dementias, would simply not be able to remain at home. By recognizing informal caregivers as “clients” in their own right and full partners in care, current caregivers are better able to continue to care, and future caregivers may be persuaded that this crucial role has merit and is doable.

Recommendation 5.4. Continue to encourage flexibility. The CSP establishes a middle path between “no strings attached” caregiver allowances which permit caregivers to purchase anything they wish, but without ongoing counselling and support, and conventional service “baskets” which limit caregivers to a pre-determined menu. As noted, the CSP uses a modest dollar amount to engage caregivers in what we have referred to as “supported self-management;” caregivers drive allocation decisions with the advice and support of professional care coordinators who can help them assess challenges, and find the best available solutions, in the process building their capacity. This recognizes that the needs of caregivers and cared-for persons vary extensively, as does access to services at the local level; for example, services available in urban areas or within mainstream cultural communities might not be available in

rural areas or within minority communities. Flexibility in resource allocation is essential, both to respond to such variation, and to engage caregivers.

Recommendation 5.5. Establish a goal-oriented accountability framework. While caregivers and care coordinators lauded the CSP’s flexibility, it generated a substantial administrative burden. Flexibility also raised questions around what might not be an appropriate use of CSP funds (e.g., alcohol, tobacco, “unconventional” benefits such as massage or a vacation). Care coordinators suggested a shift toward an accountability framework which would clarify where the line should be drawn, and which would also be “goals oriented.” For example, caregivers might be given an initial cash installment based on a care plan negotiated with care coordinators within general guidelines; subsequent installments would then depend on movement toward plan goals, with expenditures subject to audit after the fact.

Recommendation 5.6. Spread the CSP through Health Links. Health Links present new opportunities for collaboration with other providers around high needs persons and their caregivers, knowing that many have multiple needs spanning multiple providers. The CSP establishes a platform for extending and strengthening such linkages to other health and social care providers, including primary health care teams. There are good precedents. One example is *First Link*, a collaborative initiative between primary care providers and Alzheimer Societies which ensure that persons with dementia and caregivers are referred to specialized services as soon as possible after diagnosis; *First Link* was recently identified by Ontario’s Seniors Strategy Lead as a best practice to be spread across the province. The CSP offers opportunity to engage providers around the needs of “at risk” caregivers and cared-for older persons who are, or who are likely to become, high cost utilizers.

Recommendation 5.7. Encourage inter-disciplinary, inter-organization team approaches. Even as the CSP forges stronger partnerships at the organization level, it can encourage the emergence of inter-disciplinary, inter-organization care teams. Given that caregivers emerge from diverse communities, and have needs that span fields including health and social care, education, housing, transportation and income support, team approaches seem to be particularly well suited. In addition to adding considerable depth to assessments and care plans, teams can assist in the identification and dissemination of best practices. Moreover, given rapid advances in e-technologies, teams no longer need to be geographically concentrated; for example, there is growing use of technology-enabled teams in northern Ontario to support isolated communities.

Recommendation 5.8. Partner with researchers to demonstrate outcomes. While it was outside of the scope of this evaluation to measure outcomes, participants identified a range of qualitative and quantitative benefits for stakeholders that could and should be measured in the future. Most importantly, care coordinators and caregivers emphasized that even if the CSP does not redress underlying causes of stress, it does help caregivers to maintain their capacity to care for high needs older persons at home over the longer-term. Such longer-term outcomes can be demonstrated only through multi-year research programs that

systematically compare the pathways of matched cohorts of caregivers and cared-for persons participating, and not participating in the CSP. Of course, such research is complex and costly, since ideally it requires access to multiple data bases (including RAI-HC and RAI-CHA assessments), as well as health care utilization records (e.g., Institute for Clinical Evaluative Sciences (ICES) data). One option may be to partner with academic researchers who would receive access to CSP data in exchange for securing research funding.

Appendix A: One-Minute Evaluation Time 1

Caregiver Questionnaire

1. Who do you provide care for?

- | | | |
|--------------------------------------|---------------------------------|----------------------------------|
| <input type="checkbox"/> Husband | <input type="checkbox"/> Wife | <input type="checkbox"/> Partner |
| <input type="checkbox"/> Father | <input type="checkbox"/> Mother | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Neighbour | | |
| <input type="checkbox"/> Other _____ | | |

2. In a typical day, what care do you provide? (e.g. help with grooming, dressing, toileting, eating, banking, emotional support)

3. What is the most important issue (or problem) you face as a caregiver?

4. What help or assistance would you need to continue caregiving?

5. How well is the Caregiver Project for Seniors helping to meet your needs? What else would help you?

6. Please rate your satisfaction with the Caregiver Project for Seniors.

1- Very Dissatisfied			10- Very Satisfied						
1	2	3	4	5	6	7	8	9	10

7. On a scale of 1 to 10, please rate your current level of stress. On a scale of 1 to 10, how stressed do you feel regarding your caregiving role?

1- Very Stressed			10 - Not at all stressed						
1	2	3	4	5	6	7	8	9	10

Appendix B: One-Minute Evaluation Time 2

Caregiver Questionnaire (2)

1. What did you like most about the Caregiver Project?
2. What did you like least?
3. How has the Caregiver Project impacted on you and the person you care for?
4. What, if anything, would you change about the Caregiver Project?
5. Please rate your satisfaction with the Caregiver Project for Seniors.

1- Very Dissatisfied

10 - Very Satisfied

1 2 3 4 5 6 7 8 9 10

6. On a scale of 1 to 10, please rate your current level of stress. On a scale of 1 to 10, how stressed do you feel regarding your caregiving role?

1- Very Stressed

10 - Not at all stressed

1 2 3 4 5 6 7 8 9 10

Appendix C: Briefing Note on Administrative Overhead

Administering the Caregiver Framework for Seniors Project

Submitted by: Natalie Warrick, Project Coordinator

Objective

This briefing note is intended to provide an overview of the costs associated with the interventions used in the Caregiver Framework for Seniors Project (“the Caregiver Project”).

Background

The TC LHIN as part of its 2011-2014 strategic plan provided funding to the Alzheimer Society of Toronto to develop the Caregiver Project, which has revealed key lessons pertaining to at risk caregivers, their care recipients and the care coordinators who connect them to supports in the community.

Overview

The Caregiver Project is a ground-breaking initiative that supports at-risk informal caregivers of older persons with high needs. The supported self-directed approach establishes a platform for negotiating a flexible range of supports that reflect the individual circumstances of the caregivers and the person(s) they are caring for. The classification framework used by Janice Keefe (2011) is applied here, roughly organizing the Caregiver Project interventions into three streams: enhanced education for health providers, direct financial assistance and in-kind services. These supports vary by cost and also differ in terms of short and long-term value for the investment made.

Opportunities

Policymakers in Ontario agree that caregivers need support to reduce their reliance on formal care, delay premature institutionalization, and relieve cost pressure on the long-term care and health care systems. Over the last year supports for family caregivers have garnered widespread attention. This is evidenced by many good programs initiated by TC LHIN and by the province. In particular, the initiation and adoption of Behavioural Supports Ontario, the passing of the Caregiver Leave Act, and increased marketing of tax credits for family caregivers.

Challenges

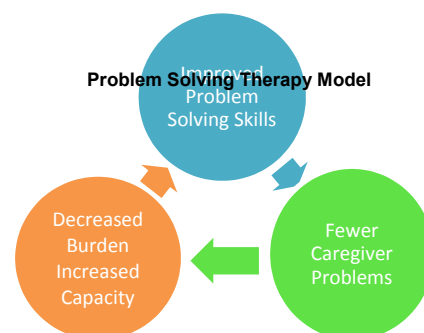
The highest users of health care resources and their caregivers need to gain timely access to the services they need, when they need them. The Caregiver Project recognizes the needs of both caregivers and care recipients. Public support for caregivers as in the Project demonstrates greater recognition of caregiving, and also serves to reinforce the good work already being done across the province to better integrate services, eliminate gaps, and effectively match needs to resources.

Interventions

Care Coordinator Education

“The project is flexible and addresses their needs.”

Care coordinators working in TC LHIN recruited caregivers to participate. Special training of care coordinators was essential because the project required a paradigm-shifting conversation between



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the care coordinator and the caregiver that is substantively different from normal practice.

Training in Problem Solving Therapy (PST) provided a practical approach. In this training, care coordinators learned to engage with caregivers in a highly focused way in order to address specific problems, agree on achievable goals and develop practicable interventions tailored to achieve those goals. Ultimately, this improves the caregiver's own ability to problem solve, which in turn helps to reduce stress and build capacity to continue caregiving. In practical terms, it also makes the most sense that the care coordinator and not the caregiver, receives the training, due to limitations on the caregiver's time. The cost of this intervention is outlined below.

Adapted from Brodaty, H. (1996). Caregivers and behavioural disturbances: Effects and interventions. *International Psychogeriatrics*, 8(Suppl3), S455-458.

Intervention	Description	Cost
Problem Solving Therapy Training Program for 80 care coordinators	<i>Facilitation by 2 psychiatrists and 2 clinicians and 3 standardized patients (Total of \$6,000 per/day@ 5 days)</i>	\$30,000
	<i>Curriculum development</i>	\$4500
	<i>Materials (handouts, PST manual, etc.) @ \$15pp Total: 80 people</i>	\$1200
	<i>Room booking (\$200/day for 5 days):</i>	\$1000
	<i>Lunch and refreshments for 5 days PST training and 4 focus groups @ \$15/pp Total: 125 people</i>	\$1875
Total		\$38,575

Rationale:

The cost of training is comparable to other full day workshops, amounting to roughly \$482/per care coordinator. PST is an evidence-based, structured, psychological intervention that has long-range value for the dollars spent. Toronto Central CCAC has also formally adopted PST training provided by Mount Sinai as part of their orientation of new coordinators, another indication that this training is high in value.

Direct Financial Assistance

"It's nice to make the decisions for myself."

Phase 1 funding extended from October 2011 to March 2012. Funding for Phase 2 caregivers spanned April 2012 to March 2013. Exceptions applied where shorter term services or one time purchases were specified. Total payouts to caregivers are outlined below. Items purchased with funding become the property of the caregiver/care recipient after their participation, thus contributing to a caregiver's long term capacity to provide best quality care. Many care plans also included services like transportation to get to medical appointments, needed supplies such as incontinence products and access to additional PSW hours. Caregivers appreciate these types of short term services, because it is a lifeline to them during periods of exhaustion, when they would be most likely to make inappropriate use of emergency department resources and/or permanently move the person in their care to a long-term care home.

Intervention	Description	Cost
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Funds to Caregivers	Care plans for 258 unique clients and 41 renewal clients(average \$1507 per client/year)	\$450,589
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Rationale:

In some cases, it was made clear that the care recipient would have moved into long-term care had funding from the project not been available to purchase a necessary piece of equipment such as a hospital bed. A few added hours of support, or the capital investment of \$1500 towards necessary home care supplies and equipment, can be the difference between supporting a senior to live independently at home or risk them entering long-term care prematurely.

In-Kind Services

“Just having someone to call...”

Counselling Sessions with Caregivers

Case management, in-depth counselling, enhanced system navigation, care planning, referral, information and caregiver education are ongoing activities that are maintained for all caregivers throughout their participation in the project. Enhanced support to caregivers in locating and coordinating services between various providers has proven to be highly effective at providing relief to their caregiving burden.

Care coordinators designed individualized care plans along with caregivers, and then followed up approximately one month after to ensure that the caregiver had carried out the tasks as outlined. This process reassured caregivers that they were being supported in their efforts to self-direct a care plan. In cases, where it was clear that the caregiver needed more assistance, efforts were made to assist them or to revise care plans as necessary to meet their changing needs.

On several occasions, care coordinators relied on the project coordinator to contact vendors and providers to cost-out supports and order services due to limitations on the care coordinators time. Care coordinators valued the flexibility they had in negotiating the care plan with the caregiver. They also placed high value on the counselling aspect of the project, and appreciated that the project approach encourages self-management of funds by the caregivers.

Intervention	Description	Cost
Case Management, Counselling, Caregiver Education, and Referral	<i>Case Management, education and referral by TC CCAC</i>	<i>Minimum 600 hrs/ yr (est. @ 2 hrs/client)</i>
	<i>Counselling, education and referral by Alzheimer Society of Toronto team</i>	<i>Minimum 600 hrs/yr</i>
	<i>Room bookings for focus groups</i>	<i>In kind</i>
Total		<i>In Kind</i>

Rationale:

Many caregivers reported an improved outlook in continuing their role, despite the fact that some reported their stress as unchanged. Several studies have demonstrated long range positive effects of

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time limited counselling with sustained benefits documented upwards of three years after the intervention (Mittelman, et al., 1995; Mittelman, Roth, Clay, & Haley, 2007; Pinquart & Sorensen, 2006).

Administrative Overhead

In addition to the direct payouts to clients and training and evaluation costs, there are administrative costs associated with the delivery of the project including 1- FTE Project Coordinator. At a minimum this person manages participant data and project expenditures, recruits agencies for specialized training programs, initiates services on behalf of caregivers, maintains ongoing relations with care coordinators and vendors, and writes reports as required. The combined total administrative cost including salary and operations expenses amounts to roughly \$141,500 annually.

As an example of how the project used best practices to inform the design and delivery of the project, the two primary methods of administering funding utilized by the project coordinator have been outlined below. Though, both methods were used, the pre-payment method offers a clear benefit in that fewer hours are spent managing the actual transfer of funds, allowing more time to be spent with clients.

<i>Invoice Method</i>	<i>Pre-Payment Method</i>
Total invoices for 1 caregiver for 12 month period: 96 invoices (to be processed)	Total invoices for 1 caregiver for 12 month period: 96 invoices (kept on record)
Tracking: photocopying, submitting invoice for approval for payment, filing the invoice, management of data records on finance sheet for each invoice.	Tracking: Invoices are filed as they are received.
Time spent by project coordinator tracking: 4hrs/mo., 48 hrs/yr.	Time spent by project coordinator tracking: 1 hr/mo., 12 hrs/yr.
Preparing a cheque for mailing: preparing remittance vouchers with each cheque per payment period and an accompanying letter that identifies the client receiving services.	Preparing a cheque for mailing: preparing remittance voucher with one cheque which acts as prepayment of services to be delivered throughout the year.
Time spent by project coordinator to prepare cheque for mailing: 2 hrs/mo., 24 hrs/yr.	Time spent by project coordinator to preparing cheque for mailing: 0.5 hour per year
Finance department: processes the invoices and prepares cheques for payment. Time spent by finance department: 1.5 hrs/mo., 18 hrs/yr.	Finance department: processes the invoices and prepares cheques for payment. Time spent by finance department: .5 hrs/mo., 6 hrs/yr.

Sustainability and Scalability

The project as designed is capable of providing ongoing support to upwards of 120 new caregivers and 50 continuing caregivers annually; a total of 170. In future delivery of the project, it must be decided whether certain caregivers designated as “very high risk” are an appropriate target of the intervention. It is conceivable that efforts should be directed towards caregivers at a lower range of risk, where there may be greater possibility of effecting positive change in their perceived level of stress. To further enhance sustainability, the project might also utilize a valid instrument of caregiver capacity as part of the assessment. Caregivers unable to self-direct would be identified and provided with further enhanced counselling and supports.

Outcomes

- The flexible approach used in the project reduced barriers and increased access to supports for at risk caregivers caring for frail seniors at home.
- The project potentially delayed a move to long-term care for 185 care recipients, in some cases for upwards of 12 months.
- We have learned who the caregivers are, what they need and the circumstances that precipitate these needs. These lessons are not only fascinating, but add valuable intelligence that is relevant to program development for key stakeholders across multiple sectors.
- Key alliances have been built between CSS, CCAC, Hospital, CMHA, and for-profit providers. These alliances proved vital especially when a care recipient transitioned from hospital to home and where funding was required to cover additional services needed to sustain them in the community.
- In aligning our goals with theirs, the coordination efforts led by the project have reinforced and strengthened the work being done by other initiatives in TC LHIN including the Caregiver Framework Project for Children, BSO, Home First, and Resource Matching and Referral (RM&R).

Conclusions

“To spend on things I would not have tried otherwise, for example, a private PSW on some evenings, a true lifesaver.”

Caregivers in the project reported high satisfaction, but fewer reported significant improvements in their level of stress. The reasons for this are multi-factorial. It is possible that during their participation in the project, their health or the health of their care recipient would have worsened, increasing the work load and making it more difficult for the caregiver to continue in their role. Other stressful aspects reported by caregivers were decreased home care hours, job loss, and increased behavioural disturbances. What is likely is that caregivers increased their capacity to cope with the stress through enhanced education provided to them by counsellors. Also, many caregivers reported feeling better able to perform their role as a caregiver, one indicator that they experienced increased mastery as a result of the intervention.

The supported self-directed technique coupled with a discretionary budget allows caregivers to pursue innovative strategies to relieve their burden. In developing the pilot and working through course corrections, the project gained key insights into the needs of the highest risk caregivers with the vast majority reporting feeling better supported and validated in their role.

In future iterations of the project, it may prove valuable to establish certain controls amongst caregivers in order that the causal relationship between the intervention and outcomes may be strengthened. As it stands, amidst a rapidly changing health care environment in which vital programs are being reduced¹ or cut completely², it is difficult to tease out which effects are a direct result of the Caregiver Project and which were the result of changes happening at the system level.

¹For example, home care hours for non-acute long stay clients.

²E.g. Hardship Fund

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