

Balance of Care Research Group
University of Toronto

Caregiver Support Project: Evaluation Interim Report

Submitted to:
Alzheimer Society of Toronto

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Executive Summary

1.0 Introduction

The Caregiver Support Project (CSP) led by the Alzheimer Society of Toronto (AST), in partnership with the Toronto Central Community Care Access Centre (TC CCAC), is a groundbreaking initiative aimed at supporting “at risk” informal caregivers of older persons with high needs. A growing weight of international evidence emphasizes the crucial role of informal and mostly unpaid caregivers not only in maintaining the independence, well-being and quality of life of cared-for older persons, but in moderating their use of costly and increasingly stretched hospital and institutional resources.

The CSP is particularly noteworthy, since instead of offering fixed services or benefits, it establishes a “platform” for negotiating flexible support packages which meet the needs of caregivers and cared-for older persons. While similar in key respects to classic “self-management” models which emphasize independent choice, but which might not be viable for highly stressed and poorly resourced caregivers, this platform is better characterized as “supported self-management”— caregiver decisions are assisted by professional case managers who understand support options and how to access them.

Also noteworthy, and a strong measure of the project’s success, is the fact that the CSP has expanded rapidly; in just a few months, it has grown to serve more than 300 informal caregivers, about 10 times the number served at start-up. In doing so, it has also expanded beyond its foundation partnership with the TC CCAC to involve five additional community agencies serving diverse populations in different parts of Toronto, and three other providers spanning acute and community-based care.

Of course, such flexibility and dynamic growth pose challenges for evaluation. Conventional evaluation clearly delineates causal relationships between well-defined interventions and well-defined outcomes, for well-defined populations. In the case of the caregiver project, the population base is fluid with new caregivers from diverse communities enrolled on an ongoing basis by different providers; there is no one set intervention since negotiated support packages vary extensively in content and cost; and a range of both “soft” (e.g., enhanced quality of life) and “hard” (e.g., fewer hospital admissions) benefits may accrue not only to caregivers, but to cared-for older persons, providers and the health care system. We therefore draw on the influential work of the Medical Research Council in the UK (2008) which suggests that complex interventions, such as caregiver supports, require complex evaluations which consider a range of outcomes, access qualitative and quantitative evidence, and take context into account.

2.0 Context

Understanding context is crucial. First, context identifies external factors that may directly or indirectly impact on the design and delivery of a program as well as its outcomes. Second, key policy trends and directions establish important “signposts” by which to judge project alignment.

The CSP directly addresses key policy priorities.

- It “targets” high needs older persons and their caregivers; all older persons enrolled in the project have been assessed as qualifying for institutional long-term care; all are potentially heavy users of health and social care; all caregivers are “at risk” of burnout and decline

- The CSP seeks to build community capacity; both caregivers and cared-for older persons benefit from relatively modest investments aimed at increasing independence, quality of life, and wellbeing, while moderating demand for more costly and sometimes unnecessary hospital and institutional care. Moreover, the project aims to prevent or delay hospitalization or institutionalization “before the fact” rather than reacting after people become ill or dependent
- The project builds working linkages between providers, thus contributing to system integration “from the ground up;” in addition to AST and TC CCAC, partners now include community based agencies serving diverse populations across Toronto.
- It aligns with recent policy priorities which aim to reduce health system costs by shifting the focus of health care services out of institutions and into communities. This shift in focus may place additional pressure on informal caregivers which may increase their needs.

The CSP responds to growing and more complex needs.

- Informal caregivers enrolled in CSP often live with cared-for older persons requiring long hours of medical and supportive care due to health problems including incontinence and dementia as well as general decline. In addition they provide crucial everyday supports for daily living including meals, homemaking, transportation to medical appointments, paying bills, and buying groceries. Many deal with physical and verbal aggression. They have little time for themselves and often limited ability to accept paid employment or to engage in recreation or social activities. All report high levels of stress.

3.0 Evaluation Data and Methods

The evaluation draws upon multiple quantitative and qualitative data sources including:

- Administrative data generated as part of the CSP describing key characteristics of participating caregivers (e.g. age, language, ethnicity etc.) as well as the type and amount of services received.
- RAI-HC (Resident Assessment Instrument – Home Care) and ED (Emergency Department) Notification data obtained from the Toronto Central CCAC for all clients in the Seniors Enhanced Care (SEC) program (N = 1554) and for 91 clients in the Caregiver Support Project (CSP).
- Qualitative results of semi-structured debriefing sessions with the TC CCAC care managers participating in the CSP.
- Qualitative results from 136 “one minute evaluations” completed by caregivers as of May, 2012.

4.0 Findings

Our findings suggest that:

- Caregivers in the CSP are more likely to be female and speak English. Almost half of the caregivers come from minority groups. Virtually all of the caregivers enrolled in the CSP were judged to be in financial need.
- As compared to the seniors in the SEC program, who themselves have needs which are sufficiently high to make them long-term care eligible, those in the CSP have even “higher needs.” Compared to SEC clients, CSP clients are
 - More likely to have high MAPLe scores

- More likely to score in the highest category of difficulty on the Instrumental Activities of Daily Living (IADL) scale
- More likely to experience high needs with the activities of daily living (ADL)
- More likely to have cognitive difficulties
- More likely to demonstrate behavioural problems

In addition:

- CSP and SEC clients receive about the same number of home care hours
- CSP informal caregivers average about 50 hours of care per week (as compared to 30 hours for SEC caregivers)
- Many CSP caregivers are willing to continue to increase the number of care hours provided
- All CSP caregivers experience high levels of stress.

TC CCAC care managers reported that:

- The process of negotiating caregiver supports was very “creative” resulting in unconventional packages including recreational activities and self-care services
- Caregivers feel more empowered because this project has increased their knowledge of the types of services available to support them
- Caregivers feel more appreciated and validated in their caregiving role, understanding that often this population of caregivers can grow to feel very alone and underappreciated by other family members and care recipients many of which suffer from dementia and cannot express their appreciation
- CSP is positively impacting on seniors as well as caregivers due to an increased capacity of caregivers to provide care
- Care managers feel good about being able to provide immediate support to caregivers thanks to the expediency of the provision of funds and services through the CSP. While counselling sessions do increase their workloads, these conversations are valuable
- CSP has increased caregiver capacity to provide care for a longer duration, and that it is therefore delaying the admission to long term care. Even after funds and services are no longer available through the CSP, increased knowledge will maintain the caregivers’ ability to provide care for their loved ones at home.

Caregivers reported that:

- They experience a range of issues which include but are not limited to the needs of the care recipient; these include financial concerns, lack of formal supports, their own personal and social needs; time management challenges
- In addition to immediate supports, to continue their caregiving roles they also require ongoing assistance with education and counseling; funding and employment; and respite
- Caregivers were appreciative of the CSP; they cited benefits in areas such as finances; self-worth; and improved morale
- A majority of caregivers said “they would not change anything” about the CSP, while an additional 24 responses suggested the CSP be continued beyond its current close date.

5.0 Conclusions

Our interim report suggests the following conclusions:

- The complexity of the policy environment is such that there are a number of initiatives and policy interventions in addition to the CSP that may impact upon caregivers and care recipients and on the outcomes of the CSP.
- There is great complexity and heterogeneity in the caregiver and care-recipient population participating in the CSP; a common feature of CSP care-recipients is that they all have high needs, even higher than those in the SEC population, itself a high needs population.
- CSP clients do not appear to receive more formal services than SEC clients. However, they do receive more informal care, particularly from spousal caregivers living in the household. This suggests not only why informal caregivers may be experiencing stress, but also their crucial role in maintaining their cared-for family members at home.
- The CSP is generating considerable creativity both on the part of care coordinators and informal caregivers. Caregiver supports provided through the CSP span a wide range including many “unconventional” supports. Perhaps more importantly, the process of negotiating these baskets is building strong links between formal care coordinators and informal caregivers, and better equipping the latter to identify problems and solutions more effectively over the longer-term. In addition to providing immediate supports, the CSP appears to provide the “value added” of increased caregiver capacity.
- Care coordinators, as well as informal caregivers, are very satisfied with the CSP. While caregivers already at high levels of stress may not experience measurable decreases in stress levels, they clearly believe the CSP has value, particularly since it acknowledges their crucial role, and since it gives them new capacity to care for their loved ones. These are important measures of success in and of themselves.
- The CSP is providing care managers an additional and important tool for supporting the “unit of care” both in the short and longer terms. For the first time, the CSP explicitly recognizes the informal caregiver as “client” both validating this important role and establishing an innovative platform for supporting high needs caregivers and care recipients as independently as possible, for as long as possible, in the community.

1.0 Introduction

As detailed in our previous proposals and reports, the Caregiver Support Project (CSP) led by the Alzheimer Society of Toronto (AST), in partnership with the Toronto Central Community Care Access Centre (TC CCAC), is a groundbreaking initiative aimed at supporting “at risk” informal caregivers of older persons with high needs. A growing weight of international evidence emphasizes the crucial role of informal and mostly unpaid caregivers not only in maintaining the independence, well-being and quality of life of cared-for older persons, but in moderating their use of costly and increasingly stretched hospital and institutional resources.

The CSP is particularly noteworthy, since instead of offering fixed services or benefits, it establishes a “platform” for negotiating flexible support packages which meet the needs of caregivers and cared-for older persons. While similar in key respects to classic “self-management” models which emphasize independent choice, but which might not be viable for highly stressed and poorly resourced caregivers, this platform is better characterized as “supported self-management”— caregiver decisions are assisted by professional case managers who understand support options and how to access them.

Also noteworthy, and a strong measure of the project’s success, is the fact that it has expanded rapidly; in just a few months, it has grown to serve more than 300 informal caregivers, about 10 times the number served at start-up. In doing so, it has also expanded beyond its foundation partnership with the TC CCAC to involve five additional community agencies serving diverse populations in different parts of Toronto, and three other providers spanning acute and community-based care. In addition to serving a growing number of caregivers and older persons, the CSP has forged stronger ties between providers, thus contributing to system integration.

Of course, such flexibility and dynamic growth pose challenges for evaluation. Conventional evaluation clearly delineates causal relationships between well-defined interventions and well-defined outcomes, for well-defined populations. In the case of the caregiver project, the population base is fluid with new caregivers from diverse communities enrolled on an ongoing basis by different providers; there is no one set intervention since negotiated support packages vary extensively in content and cost; and a range of both “soft” (e.g., enhanced quality of life) and “hard” (e.g., fewer hospital admissions) benefits may accrue not only to caregivers, but to cared-for older persons, providers and the health care system.

Moreover, this project takes place in a volatile environment characterized by economic downturn and constraints on public spending and services, which also impact on caregivers and older persons, and which may offset the impact of caregiver supports. Further, by definition, high needs older persons are unlikely to “get well;” regardless of the quality or appropriateness of the supports they and their caregivers receive, they will decline, use health and social resources including hospital emergency rooms, and eventually die. The project is only one of many factors simultaneously impacting on caregivers and older persons.

While this does not preclude rigorous evaluation, it does make evaluation more complex and nuanced. Here we draw on the influential work of the Medical Research Council in the UK (2008) which suggests that complex interventions, such as caregiver supports, require complex evaluations which consider a range of outcomes, access qualitative and quantitative evidence, and take context into account (for details go to www.mrc.ac.uk/complexinterventionsguidance). In this interim report, we therefore begin by outlining the context for the caregiver support project and our evaluation, and then go on to provide initial quantitative and qualitative findings which we expect to elaborate as the project rolls out.

2.0 Context

2.1 A Complex Policy Environment

As noted, understanding context is crucial. First, context identifies external factors that may directly or indirectly impact on the design and delivery of a program as well as its outcomes. Second, key policy trends and directions establish important "signposts" by which to judge project alignment.

A number of recent reports and policy documents shape the current context for the CSP (more details are provided in an appendix). In brief, they suggest that:

- Public spending is now outpacing revenues; particularly in this current period of economic downturn, reductions in spending are required to manage deficits.
- Health care accounts for the largest share of public spending in Ontario, as in other provinces, and health care costs continue to grow faster than the rate of economic growth; if not contained, it is estimated that health care spending could account for up to 80% of all provincial spending by 2030, thus eroding health system sustainability while also placing massive constraints on public capacity to fund other crucial programs (e.g., education and housing) which are determinants of health.
- The health care system requires extensive reform and restructuring to control costs and produce better outcomes. This includes:
 - Greater attention to "high risk" individuals and families with complex, chronic needs; 1% of the population accounts for approximately 35% of health care costs; 10% accounts for approximately 79% of costs.
 - Increased emphasis on community-based care in order to maintain older persons at home instead of in hospitals or long-term care homes where they are more costly to treat.
 - Strengthened capacity to discharge hospital patients (including older persons) faster by providing appropriate discharge options in the home and community.

Similar directions are reflected in a number of provincial strategies and policy statements. These include:

- **The Ontario Wait Times Strategy.** This strategy emphasizes the need to find ways to reduce the number of hospital Alternate Level of Care (ALC) beds, beds occupied by individuals no longer requiring acute care but who cannot be discharged because of a lack of community-based care alternatives. Possible options include increased funding of "home care services and enhanced integration between hospitals and the community."
- **Aging at Home Strategy.** In August 2007, the government of Ontario launched a four year, \$1.1 billion strategy to provide enhanced community living options for seniors. The strategy was implemented through the LHINs and was expected to relieve pressure on hospitals and long-term care homes by supporting older persons at home for as long as possible, and by moving ALC patients to more appropriate settings as quickly as possible.
- **Excellent Care for All Strategy (ECFA).** Announced in 2010, ECFA includes four components: the Excellent Care for All Act, 2010, the expansion of the role of the Ontario Health Quality Council, Patient-Based Payment, and evidence-based practice. This strategy provides incentives to hospitals that achieve reductions in such areas as ALC days, lengths of stay, and readmissions. Also included are incentives for hospitals to implement evidence-based discharge practices and

establishing better linkages with the community.

- **Ontario's Action Plan for Health Care.** This 2012 document emphasizes the province's commitment to ensuring that individuals are at home instead of in hospitals or long-term care. In particular, it points to system structuring aimed at better meeting the needs of "today's population, with more focus on seniors and chronic disease management."

How does the CSP align with these provincial policy directions and priorities?

A first observation is that the CSP directly addresses many of these priorities. For example,

- The project "targets" high needs older persons and their caregivers: all older persons enrolled in the project have been assessed as qualifying for institutional long-term care; all are potentially heavy users of health and social care; all caregivers have been assessed as "at risk" of burnout and decline
- The CSP seeks to build community capacity; both caregivers and cared-for older persons benefit from relatively modest investments aimed at increasing independence, quality of life, and wellbeing, while moderating demand for more costly and sometimes unnecessary hospital and institutional care. Moreover, the project aims to prevent or delay hospitalization or institutionalization "before the fact" rather than reacting after people become ill or dependent
- The project builds working linkages between providers, thus contributing to system integration "from the ground up;" in addition to AST and TC CCAC, partners now include community based agencies serving diverse populations across Toronto.

A second observation is that while it does not directly address other key policy priorities, particularly the emphasis on discharging ALC patients more quickly from hospitals, it potentially does so indirectly.

- While there are few demonstrated linkages between caregiver supports and earlier hospital discharges, plausible arguments can be made that more resilient caregivers can help to avoid or delay hospital and institutional care for high needs older persons and for themselves before the fact.

A third observation is that the CSP may still face structural challenges to achieving its aims. For example,

- Recent CCAC data suggest that increasing proportions of available home care resources are being directed toward post-acute care clients, with proportionately less available to prevent or delay hospital and institutional care. Recently announced budget increases of about 4% for community-based care may allow a renewed focus on prevention and maintenance. Nevertheless, tighter access to home care services, in a context of more tightly constrained public spending, could itself contribute to informal caregiver burden and stress, offsetting the impact of the CSP.

2.2 Complex and Growing Needs

In this complex and dynamic policy environment, the CSP also addresses increasingly complex and diverse needs of caregivers and care-recipients. The following vignettes, based on observations from the project to date, give a sense not only of that diversity and complexity, but of the heavy burden taken on by many informal caregivers, which in their absence, would necessarily default to hospitals or long-term care.

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 for her husband 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 briefs. She then prepares a special breakfast that requires that she 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 by changing her husband's diaper and dressings. Since her husband does not like receiving care from nurses, the pressure on Julia is exacerbated. The only respite comes from two daily visits from a personal support worker. With the constant pressure placed on her, Julia has little time to care for herself. She suffers from a lack of sleep — she is often awoken in the middle of the night to support her husband through pains caused by Parkinson's symptoms — has little time visit her family, or even do simple things like personal hygiene or cooking meals for herself. She also had difficulty managing her diabetes, high-blood pressure and osteoarthritis. Lately, Julia reports suffering from depression after not being able to attend her grandson's wedding, and increasing stress caused by the financial burden of her husband's rising care costs.

Nancy

Nancy recently moved into her parents' home when their family doctor said her mother required 24/7 care. Both of Nancy's parents suffer from dementia. She tries to let them do as much as possible on their own, but as they both decline, Nancy is finding she is required to make most of the decisions around the home and doing more and more to take care of them. This includes providing emotional support for her mother every evening to help her settle in for bed, dealing with her mother's anxiety and physical aggression, accompanying her parents to all medical appointments, sorting mail, paying bills, grocery shopping, preparing meals, changing incontinence diapers, and dressing and bathing her parents. With all this pressure, Nancy is finding it difficult to cope. In particular, the emotional impact of caring for her parents is more intense than she anticipated. She is frustrated by how little her parents are able to do for themselves, and how difficult it is to get them to do the things they need to do to care for themselves. Nancy cares for her parents from 9 AM to 9 PM almost every day, and she hardly sleeps since she is up several times throughout the night to care for her mother. Nancy has very little income because she is unable to work and is unable to make any definite plans outside of the home given her parents' constant care needs.

2.3 The CSP: A Complex Intervention

These vignettes offer important insight into the complex health and social needs of caregivers and care-recipients. They also point to the importance of delivering caregiver support packages which best meet individual needs. The following vignette, again based on experience from earlier stages of the project, provides insight into the complexity of the CSP project, which is not a single clinical intervention, but perhaps better characterized as a “platform” for negotiating the best use of available resources.

Dorothy and Julia

During their conversations, Dorothy (the TC CCAC care manager) and Julia (the caregiver introduced in the vignette above) would work together to identify which problems were causing Julia the most distress. First, Dorothy and Julia determined that Julia required time away from her caregiving duties to attend to her own health needs and to have time to spend 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. Conversation also revealed that Julia was becoming increasing

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. So, 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.

3.0 Evaluation Data and Methods

Reflecting these layers of complexity, the evaluation draws upon multiple quantitative and qualitative data sources. It is important to note that the bulk of these data have only recently become available to the evaluation team; thus, as detailed below, analysis to this point is both descriptive and preliminary.

3.1 Ethics Review and Data Transfer

The evaluation team sought and received ethics approval to conduct secondary analysis of anonymized TC CCAC client assessment and utilization data; anonymized administrative data collected by AST as part of the conduct of the CSP; and anonymized results of “debriefing” sessions conducted with TC CCAC case managers engaged in the CSP. Expedited ethics approval was obtained from two sources:

- The University of Toronto Health Sciences Research Ethics Board (REB)
- The Joint Bridgepoint Health-West Park Healthcare Centre-Toronto Central Community CareAccess Centre- Toronto Grace Health Centre Research Ethics Board (JREB)

In addition, in June of 2012 a formal *Data Sharing Agreement* was signed with the TC CCAC. Among its requirements, this agreement restricts disclosure or transfer of TC CCAC data, requires appropriate safeguards to identification of individuals or unauthorized use, and prohibits contact with TC CCAC clients.

3.1 Secondary Analysis of AST Administrative Data: Caregivers in the CSP

AST administrative data generated as part of the CSP describe key characteristics of participating caregivers (e.g. age, language, ethnicity etc.) as well as the type and amount of services received. An initial anonymized cut of these data was received by the evaluation team in December of 2011; analysis was commenced upon receipt of ethics approval. Frequencies and descriptive statistics are presented below.

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

RAI-HC (Resident Assessment Instrument – Home Care) and ED (Emergency Department) Notification data were obtained from the TC CCAC for all clients in the Seniors Enhanced Care (SEC) program (N = 1554) and for 91 clients in the Caregiver Support Project (CSP). While received in December 2011, analysis of these data did not commence until ethics approval was received.

Descriptive statistical comparisons were made between SEC clients (in effect, the “control” group) and the CSP clients (in effect the “experimental” group) using Pearson’s Chi-Square. P-values of less than or equal to 0.05 are reported in the tables below.

The ED Notification Data were used to compare numbers of ED visits in the six months prior to December 2011, among SEC and the CSP clients. Means were compared using an independent t-test.

3.3 Secondary Analysis of Community Support Agency RAI-CHA Assessment Data

RAI-CHA (Resident Assessment Instrument – Community Health Assessment) data are currently being generated for CSP clients enrolled by participating Community Support Agencies (CSA). Because these data are comparable to TC CCAC RAI-HC data, they will allow for comparisons between TC CCAC clients and CSA clients. However, these data are not yet available.

3.4 TC CCAC Care Coordinators' Debriefing Sessions

In order to identify, document and continuously learn from issues and experiences 'on the front lines,' the evaluation team conducts semi-structured debriefing sessions with the TC CCAC care managers participating in the CSP.

A first wave of three debriefing sessions was conducted between October 31st and December 22nd, 2011. Questions focused on:

- Initial impressions of the project
- How decisions were made around selecting caregivers to participate in the project and determining the basket of services which caregivers receive
- The most important challenges experienced
- The most important opportunities moving forward

A second wave of debriefing sessions began on June 14th, 2012 and will continue over the next 2 months. Questions address:

- Possible changes over time in how case managers and caregivers decide on and select services
- The impact of the CSP on caregivers, care recipients, case managers and the health care system

3.5 Caregiver One Minute Evaluations

As part of the CSP, AST generates administrative data on caregivers not available through the RAI-HC (or the RAI-CHA). These data are derived from a short, open-ended written questionnaire completed by caregivers at intake, and throughout their involvement in the CSP.

The evaluation team received 136 "one minute evaluations" that were completed by caregivers and sent to AST as of May, 2012. We note here that not all the evaluations were completed in their entirety. The evaluation team conducted a content analysis on the one minute evaluations using Nvivo9. As the project rolls out the "one minute evaluations" will be analyzed to assess changes over time and will be linked to the TC CCAC administrative data in order to assess trends over the course of the Project.

4.0 Findings

4.1 Secondary Analysis of AST Administrative Data: Caregivers in the CSP

The table below presents baseline descriptive information for the 91 caregivers enrolled in the CSP project as of December 2011.

Characteristic	Label	Avg. (%)
About the Caregiver		
Age		69.3
Gender	Male	25.3
	Female	74.7
Language	English	67.0
	Other	33.0
Ethnicity	Caucasian	50.5
	Other	49.5
Observed Financial Need	Yes	97.8
	No	0.2

Caregivers in the CSP are more likely to be female and speak English. Almost half of the caregivers come from minority groups. Virtually all of the caregivers enrolled in the CSP were judged by TC CCAC care managers to be in financial need.

4.2 Secondary Analysis of TCCCAC RAI-HC and ED Notification Data

The table below compares key characteristics of 1,554 SEC clients to those of the 91 CSP clients (as of December 2011). Note that the data in the first table “about the senior” measure characteristics of the cared-for older person, not the caregiver.

The X² 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.

Characteristics	Label	Value	SEC		CSP		X ² p-Value
			N	%	N	%	
About the Senior							
Age	≤60	≤60	3	0.2	2	2.2	0.000*
	61 - 79	61 - 79	372	23.9	39	42.9	
	≥80	≥80	1179	75.9	50	54.9	
Language	English	1	880	56.6	39	42.9	0.010*
	Other	0	674	43.4	52	57.1	
Maple Scale	Low	1	18	1.2	0	0.0	0.000*
	Mild	2	16	1.2	0	0.0	
	Moderate	3	511	32.9	20	22.0	
	High	4	626	40.3	36	39.6	
	Very High	5	382	24.6	33	36.3	

IADL Difficulty Scale	No Difficulty	0	4	0.3	0	0.0	0.001*
	Some Difficulty	1	5	0.3	0	0.0	
	Some Difficulty	2	26	1.7	0	0.0	
	Some Difficulty	3	11	0.7	0	0.0	
	Great Difficulty	4	112	7.2	1	1.1	
	Great Difficulty	5	705	45.4	26	29.2	
	Great Difficulty	6	691	44.5	62	69.7	
ADL Hierarchy Scale	Independent	0	275	17.7	7	7.9	0.000*
	Some Assistance	1-2	689	44.3	28	31.5	
	Dependence	3-6	590	38.0	54	60.7	
Cognitive Performance Scale	Borderline Intact	1	156	10.0	6	6.7	0.000*
	Mild Impairment	2	684	44.0	28	31.5	
	Severe Impairment	3-6	583	37.5	54	60.7	
Verbally Abusive Behaviour	No	0	1439	92.6	76	85.4	0.014*
	Yes	1 or 2	115	7.4	13	14.6	
Physically Abusive Behaviour	No	0	1522	97.9	83	93.3	0.004*
	Yes	1 or 2	32	2.1	6	6.7	
CAP Behaviour	Triggerred	1	316	20.3	29	31.9	0.000*
	Not Triggerred	0	1238	79.7	60	65.9	

As compared to the seniors in the SEC program, who are themselves, long-term care eligible, those in the CSP are even “higher needs.”

Specifically, while CSP clients tend to be somewhat younger (averaging 82 years as compared to 84 years for those in the SEC program), they are:

- Less likely to speak English -- 43% of SEC clients versus 57.1% of the CSP clients speak a language other than English
- More likely to score as high needs on the MAPLe (Method for Assigning Priority Levels) scale, a widely used index of need -- 36.3% of the CSP versus 24.6% of SEC clients score Very High
- More likely to score in the highest category of difficulty on the Instrumental Activities of Daily Living (IADL) scale – 44.5% of SEC clients versus 69.7% of CSP clients have such high scores
- More likely to experience high needs with the activities of daily living (ADL) -- 60.7% of CSP clients versus 38% of SEC clients score in the high needs range of the ADL Hierarchy scale
- More likely to have cognitive difficulties -- 60.7% of the CSP clients versus 37.5% of SEC clients score in the severe impairment range of the Cognitive Performance Scale
- More likely to demonstrate behavioural problems
 - 14.6% of CSP clients are verbally abusive versus 7.4% of SEC clients
 - 6.7% of CSP clients are physically abusive versus 2.1% of SEC clients
 - 31.9% of CSP clients triggered the Behaviour CAP indicating a need for a behavior intervention, versus 20.3% of SEC clients.

It is worth noting that behavioural and “heavy care” ADL needs are widely acknowledged in the literature as key sources of caregiver distress and burnout.

The data in the following table show that in spite of these higher needs, CSP clients do not receive significantly more formal home care than SEC clients. In fact, additional care may come mostly from informal caregivers, usually spouses living at home.

Characteristics	Label	Value	SEC		CSP		X ² p-Value
			N	%	N	%	
Mix of Formal and Informal Supports							
Formal Service Utilization (hours)	0	0	208	13.6	10	11.2	0.852
	1-25	1-25	1143	74.8	67	75.3	
	26-50	26-50	98	6.4	5	5.6	
	51-75	51-75	28	1.8	3	3.4	
	75-100	75-100	9	0.6	1	1.1	
	100+	100+	42	2.7	3	3.4	
Area of Help: IADL care	Yes	0	1360	89.1	89	100	0.001*
	No	1	167	10.9	0	0.0	
Area of Help: ADL care	Yes	0	800	52.4	76	85.4	0.000*
	No	1	727	47.6	13	14.6	
Extent of Informal Weekday Hours of Care	0	0	64	4.2	0	0.0	0.000*
	1-25	1-25	1091	71.7	44	49.4	
	26-50	26-50	277	18.2	27	30.3	
	51-75	51-75	46	3.0	13	14.6	
	75-100	75-100	30	2.0	4	4.5	
	100+	100+	13	0.9	1	1.1	
Extent of Informal Weekend Hours of Care	0	0	94	6.2	1	1.1	0.001*
	1-25	1-25	1366	89.8	77	86.5	
	26-50	26-50	60	3.9	11	12.4	
	51-75	51-75	0	0.0	0	0.0	
	75-100	75-100	0	0.0	0	0.0	
	100+	100+	1	0.0	0	0.0	
Caregiver Lives with Client	Yes	0	800	51.5	75	84.3	0.000*
	No	1 or 2	754	48.5	14	15.7	
Relationship to Client	Child or Child-In-Law	0	891	58.3	38	42.7	0.000*
	Spouse	1	416	48.0	48	53.9	
	Other Relative	2	128	8.4	3	3.4	
	Friend/Neighbour	3	92	6.0	0	0.0	
Willingness to Increase Emotional Support	Willing	0 or 1	899	60.1	63	70.8	0.044*
	Not Willing	2	598	39.9	26	29.2	
Willingness to Increase IADL Support	Willing	0 or 1	488	32.6	45	50.6	0.000*
	Not Willing	2	1009	67.4	44	49.4	
Caregiver Unable to Continue Caring	Yes	1	246	15.8	26	29.2	0.001*
	No	0	1308	84.2	63	70.8	
Caregiver Expresses Feelings of Distress, Anger or Depression	Yes	1	552	35.5	58	65.2	0.000*
	No	0	1002	64.5	31	34.8	
Caregiver Distress	Yes	1	661	42.5	64	70.3	0.000*
	No	0	893	57.5	27	29.7	

Overall,

- Caregivers in the CSP are more likely to be spouses of the care recipients (53.9%) than those in the SEC program (48%)
- While CSP clients receive slightly more formal home care hours per week than those in the SEC program -- 17.78 hours of formal care, versus 16.47 hours among SEC clients -- there is no significant difference
- Informal caregivers in the CSP providing more hours of care than their counterparts in the SEC program -- Informal caregivers of the CSP care recipients average 34.97 hours of care during the week and 14.94 hours of care on weekends (for a total of almost 50 hours) compared to SEC caregivers who average 20.51 and 9.17 hours of care during the week and weekends (for a total of about 30 hours) respectively.
- Nevertheless, caregivers in the CSP are still more likely to be willing to increase the amount of time they spend in caregiving activities -- just over 70% of CSP caregivers state they are willing to increase the amount of time providing emotional support, and 50.6% stated they are willing to increase the amount of time they spend providing IADL support. This compares to 60.1% of caregivers in the SEC who state they are willing to increase the time spent on emotional support, and 32.6% who state they are willing to increase the time spent on IADL support.

Perhaps as a consequence of their caregiving activities, caregivers in the CSP also score higher on indices associated with stress and distress. Caregivers in the CSP are more likely to:

- State they are 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)

The table below compares the number of Emergency Department (ED) Admissions among SEC and CSP clients over age 80 in the six months period April – September 2011, that is, prior to their enrolment in the CSP.

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

As the above table indicates, although there was a higher mean number of ED Admissions among seniors over age 80 in the SEC compared to seniors in the CSP, this difference was not statistically significant.

4.3 TC CCAC Care Coordinators' Debriefing Sessions

In our Preliminary Report (January 2012) we reported on the results of the first wave of debriefing sessions conducted with the CCAC care coordinators participating in the CSP. In brief, the key findings of these sessions suggested the following:

- Care coordinators consider a variety of factors when selecting caregivers to be included in the CSP, including but not limited to:
 - family support available to caregivers
 - family income

- presence of cultural barriers
 - caregiver risk of mental and physical health problems
- Care coordinators valued the ability to use flexibility in determining the mix of services they put in place to support caregivers
- Care coordinators placed high value on the counselling aspect of the program and believed that any future program which encourages self management of funds by caregivers also includes this dimension
- Care coordinators believed that potential impacts of the project might include:
 - Maintenance of caregivers' current abilities (or prevention of deterioration)
 - Reductions in the number of crisis applications for long-term care
 - Improvements in the social, emotional and physical needs of the caregiver
 - Reductions in caregiver burden on measurement scales

On June 14, 2012 the first Wave 2 CCAC care coordinator debriefing session was conducted with seven SEC care coordinators participating in the CSP. Because of limited time, care coordinators were asked only two questions:

- Whether or not there have been significant changes, since the beginning of the project when they were first debriefed, related to the conversation they have with caregivers about determining which services to provide
- Whether they believe that the CSP will have an impact on the caregivers, the care recipients, the care coordinators and the health care system

Care coordinators offered a number of important insights into changes over the course of the project. For example, they stated that they had become more familiar and more comfortable with “creative” services, such as recreational activities and self-care services that aren’t typically in the “tool box” of CCAC care coordinators such as massages and theatre tickets.

Care coordinators also stated that when they visited caregivers for the second time to re-assess and provide additional services, the conversations progressed easier than the initial meetings. Care coordinators attributed this change to the fact that caregivers had become more comfortable focusing on their own needs, as opposed to only focusing on the needs of the care recipient. As caregivers got more used to the idea of receiving services for themselves, they were better able to articulate which services would help relieve their burden.

We also asked care coordinators about their impressions of how the CSP is impacting on caregivers, care recipients, care coordinators and the health care system. Care coordinators unanimously agreed that the CSP is positively impacting on the caregivers in the project. Care coordinators believed that the caregivers feel more empowered because this project has increased their knowledge of the types of services available to support them, above and beyond the services they received through the CSP. In addition care coordinators believed that caregivers feel more appreciated and validated in their caregiving role thanks to their participation in the CSP, understanding that often this population of caregivers can grow to feel very alone and underappreciated by other family members and care recipients many of which suffer from dementia and cannot express their appreciation.

Care coordinators also believe that the CSP is positively impacting on the seniors (care recipients) in the CSP. They believed that the benefits to the seniors are attributed to the increased capacity of caregivers to provide care thanks to the reduced stress and burden on caregivers in the CSP.

When asked about how the CSP is impacting on the care coordinators themselves, the majority felt positive about their participation in the CSP. Care coordinators stated that they feel good about being able to provide immediate support to caregivers thanks to the expediency of the provision of funds and services through the CSP, especially compared to the reality of most services they administer which tend to have long waiting lists. They also stated that while the counselling sessions do increase their workload, they feel that in the long run the conversations they have with caregivers cover areas that are valuable and important to discuss, and would likely need to be covered eventually over the course of their involvement with the families.

Finally, when asked about the potential for the CSP to impact on the health system, care coordinators stated that although it would be difficult to demonstrate, they believe that the caregivers in the CSP have increased capacity to provide care for a longer duration, and that therefore the CSP is delaying the admission to long term care for the seniors in the CSP. They stated that even if the CSP delays long-term care admission by one month that will result in savings for the health system. In some cases they believed that thanks to the CSP caregivers have become more aware of the variety of services available to help them, and that even after funds and services are no longer available through the CSP, that increased knowledge will maintain the caregivers' ability to care for their loved ones at home.

4.4 One Minute Evaluations

There were a total of 136 one minute evaluations completed and analyzed for this report. The one minute evaluations were filled out at two points in time. Some caregivers did not complete both one-minute evaluations as some caregivers filled out the first and not the second and vice versa.

The following themes were identified from the analysis of the one-minute evaluations and support the policy scan and the quantitative analysis conducted to date. Overall the responses from the one-minute evaluations summarized the complexity of the system, the complexity of the informal caregiver's experiences and the complexity of the outcomes as it relates to individual circumstances. The one-minute evaluations help us understand the dynamics of the caregiver relationship to the care recipient and the system.

4.4.1 Most Important Problem or Frustration

Caregivers who responded to the question **"What is the most important issue (or problem) you face as a caregiver?"** identified that the emotional impact, the high needs of the care recipient, the lack of formal and informal support, the physical impact, the lack of time and the social impact concern them the most. The responses to this question highlighted the complexity of the system, the needs of informal caregivers and the needs of the care recipients.

The evaluation team highlighted several themes that were derived from the responses to this question. There were five general themes that include:

- Needs of the care recipient
- Financial concerns
- Lack of formal supports
- Personal and social needs of the caregiver
- Time management challenges

The responses to this question stressed the complexity of the caregiving role. Caregivers have complex needs and have to navigate a complex system of supports and they highlighted many problems and frustrations that they face on a day-to-day basis related to the complexity of their situation.

4.4.2 What Caregivers Need

Caregivers who responded to the question **“What help or assistance would you need to continue caregiving?”** identified extra support as the primary requirement for continuing. The type of support varied between counselling, funding, and generally more hours to provide varied opportunities like employment, respite, and time for themselves. The responses to this question – while overall the idea of ‘more support’ is simple – highlight the complexity of individual circumstances. ‘More support’ was classified in many ways with the hope to achieve various outcomes like ‘more time for myself’ or ‘to maintain employment’

The evaluation team highlighted 3 main themes that were present within the responses to this question:

- Education and Counselling
- Funding and Employment
- Time for Myself: Increased Hours and Respite

Again, the responses to this question highlight the complexity of caregiver needs. The analysis found that the caregiving role impacts on caregivers differently and therefore the outcomes of supports might vary based on the individual circumstances.

4.4.3 How Well the CSP Responds

The responses to the question **“How well is the caregiver project for seniors helping to meet your need? What else would help you?”** asked upon initiation into the project had similar responses to the question **“How has the caregiver project impacted on you and the person you care for?”** that was asked during the second phase of one minute evaluations. These responses were positive and overall supportive of the CSP. Caregivers mainly focused on the financial impact, the impact on their relationships, and the impact on time for themselves.

The words used most frequently when responding to this question were ‘helpful’, ‘assistance’ and ‘support’. Interestingly the words ‘thank’ ‘appreciate’ and variations of these words that are similar in meaning were used demonstrating caregivers gratitude for the project. The evaluation team identified 5 major themes that were derived out of the initial one minute evaluation:

- Financial
- Increase in time for self and in self-worth
- Capacity to sustain the environment
- Improved morale
- Positive impact

The responses to 4.4.1 and 4.4.2 outlined the complexity of individualized circumstances and suggested that the impact of the CSP might vary depending on the individual complex circumstance. Therefore, it is possible that the flexibility of the CSP has the potential to benefit various individuals who need various supports ‘in order to continue’.

Caregivers who responded to the ‘impact’ questions rated the impact of the CSP positively. However, the extent of the impact, and the areas in which they felt there would be an impact varied among respondents. Caregivers responded positively to the flexibility of the CSP and reported that the CSP has the potential to benefit individual caregivers with individualized needs. The impact of the CSP on caregivers varied based on caregivers’ current complex situations. For example, some caregivers mentioned they benefited from the financial component because they were simply able to purchase needed equipment and others highlighted how using the funds to pay for extra help made them feel

emotionally supported. Therefore, while the main support was ‘funding’ the outcome for caregivers varied depending on their current situation.

Caregivers highlighted that the CSP had a positive impact on them because: it allowed them to have greater control over their own lives; it improved their financial situation; it improved their ability to take care of themselves and; it ultimately improved their relationship with friends, family and the loved one they care for.

Only 3 caregivers stated that the project had no or a negative impact. For example, one caregiver mentioned “viable option for relief. No difference/impact to my mom”. The majority of caregivers stated the CSP had a positive impact as they expressed that the CSP reduced stressed, improved their sense of control over their own life, reduced financial burden, and improved relationships and morale.

4.4.4 Most and Least Liked Aspects of the CSP

Caregivers were sent a second one minute evaluation that focused more broadly on their experiences and satisfaction with the project. The questions “**What do you like most about the caregiver support project for seniors?**” and “**What do you like least about the caregiver support project?**” were asked. Caregivers responded positively with many people replying to the latter question with statements like “nothing, it’s great!!! Thank you” and “that it is ending. Actually, I feel stress thinking about the project coming to an end”. Other caregivers stress that “they like everything about it”.

The evaluation team identified 5 key themes that emerged from the qualitative data analysis of these two questions.

- Complex administration
- Information and knowledge
- More of what’s good
- Financial contribution
- Extra Care and Moral Support

4.4.5 What Caregivers Would Change

Caregivers responded to the question “**What, if anything would you change about the caregiver project for seniors?**” very positively. Similarly to the questions “What do you like least about the caregiver project for seniors” and “what do you like most about the caregiver project for seniors” the responses were very positive and the vast majority of the responses suggested that they would change either ‘nothing’ or do ‘more of a good thing’. There were 21 responses stating they would not change anything and 24 responses suggested that, if possible, the project should be maintained for the long-term. Negative feedback was rare and at times not specific to the caregiver project, but rather a response about the overall complexity of the H&CC system.

5.0 Conclusions and Next Steps

5.1 Conclusions

Our interim report suggests the following conclusions:

- The complexity of the policy environment is such that there are a number of initiatives and policy interventions in addition to the CSP that may impact upon caregivers and care recipients and on the outcomes of the CSP.
- The policy context, particularly the allocation of financial and human resources in the H&CC sector is changing. Current emphasis appears to be focused on moving post-acute care patients out of hospital and into the community faster, often a labour-intensive job particularly for those with high needs waiting for long-term care. This may mean fewer home care and other community resources are available to address the needs of individuals prior to hospitalization, possibly increasing informal caregiver burden. If this were the case, it could be that a substitution effect may be taking place, where additional CSP resources fill a gap between needs and supports.
- There is great complexity and heterogeneity in the caregiver and care-recipient population participating in the CSP. CSP participants range from spouses caring for their partners, even as they address their own health care needs, to children caring for their aging parents.
- The common feature of CSP care-recipients is that they all have high needs, even higher than those in the SEC population, itself a high needs population. While available data cannot demonstrate that they are part of the “1%” of highest care utilizers increasingly targeted by policy-makers, they are certainly close. At the very least we know their needs are sufficiently high that they all qualify for long-term care admission.
- Regardless of these high needs, CSP clients do not appear to receive more formal services than SEC clients. However, they do receive more informal care, particularly from spouse-caregivers living in the household. This suggests not only why informal caregivers may be experiencing stress, but also their crucial role in maintaining their cared-for family members at home. While the ED data do not demonstrate that informal caregiving leads to fewer ED visits, it suggests this as a possibility to be followed up as the CSP rolls out.
- The CSP is generating considerable creativity both on the part of care coordinators and informal caregivers. Caregiver supports provided through the CSP span a wide range including many “unconventional” supports. While we hope to learn more about how well these work for different caregivers in different circumstances, it is clear that the “basket” of services is highly individualized. But perhaps more importantly, the process of negotiating these baskets is building strong links between formal care coordinators and informal caregivers; in addition to the direct services provided, these negotiations, and the problem-solving that goes with them, appears to be better equipping informal caregivers to identify problems and solutions more effectively over the longer-term, potentially beyond the CSP itself. In addition to providing immediate supports, the CSP appears to provide the “value added” of increased caregiver capacity.

- Care coordinators, as well as informal caregivers, are very satisfied with the CSP. While caregivers already at high levels of stress may not experience measurable decreases in stress levels, they clearly believe the CSP has value, particularly since it acknowledges their crucial role, and since it gives them new capacity to care for their loved ones. These are important measures of success in and of themselves.
- Finally, in addition to benefitting informal caregivers and care recipients, the CSP is providing care managers an additional and important tool for supporting the “unit of care” both in the short and longer terms. For the first time, the CSP explicitly recognizes the informal caregiver as “client” both validating this important role and establishing an innovative platform for supporting high needs caregivers and care recipients as independently as possible, for as long as possible, in the community.

5.2 Next Steps

We will continue to investigate the relationships between participation in the CSP and caregiver and care-recipient outcomes in future work. Our next steps for our analysis include the following:

- Multivariate regression analysis
- Analysis of post-intervention data (second time point)
- More exacting quantitative and qualitative analysis of the CSP participant outcomes (e.g., ER visits)
- Cost implications of CSP.

Appendix A: Additional Details of Policy Scan

I. Complex Policy Context

The CSP is being implemented in a complex policy environment that involves a great deal of uncertainty, both in terms of H&CC policy and in terms of the availability of future funding in a context of economic recession and fiscal restraint. On the other hand, the CSP has the opportunity to align with a number of recent priority initiatives being implemented provincially and with the recommendations contained in influential reports to the government that could potentially shape future policy for H&CC services. In this section we provide a brief summary of recent policy initiatives and key policy reports.

II. Commission on the Reform of Ontario's Public Services ("Drummond Report")

The Drummond Report was commissioned in order to provide recommendations to the Ontario government to address the rising costs of public services. The Drummond Report suggests that Ontario's revenues now do not cover its spending — in 2010-11 the government had a deficit of \$14 billion — and that tougher fiscal measures are needed. The Drummond Report pays close attention to Ontario's healthcare system, which it estimates will cost the Ontario government \$64.46 billion by 2017-18 if significant efforts are not made to curb spending growth in the sector. The Report makes a number of recommendations to address these increasing costs, including recommendations that directly and indirectly impact the H&CC sector. These recommendations are as follows:

- Long-term care, community care and home care are currently underfunded, with too much emphasis on long-term care facilities and too little integration of services. There should be more integration, and more weight given to home care.
- Increase the use of home-based care where appropriate to reduce costs without compromising excellent care. For example, home-based care should be used more extensively for recovery from procedures such as hip and knee surgery.
- Resist the natural temptation to build more long-term care facilities for an aging population until the government can assess what can be done by emphasizing to a greater extent the use of home-based care that is supported by community services. Home-based care is less expensive and should generate greater population satisfaction.
- Create policies to move people away from impatient acute care settings by shifting access to the healthcare system away from emergency rooms and towards community care (i.e., walk-in clinics and Family Health Teams), home care and, in some cases, long-term care.

III. Therapy or Surgery? A Prescription for Canada's Health System

Drummond (2011) provided similar recommendations in his recent CD Howe Institute report called "Therapy or Surgery? A Prescription for Canada's Health System." In that report, Drummond suggests that if the status quo is maintained, healthcare costs will grow 6.5% annually so that healthcare will account for 80% of Ontario's public expenditure by 2030. The report suggests that much of this increase in costs can be mitigated by smarter spending, including several reforms that directly and indirectly impact the H&CC sector:

- Place a larger emphasis on home care due to an increase in the impact of chronic disease
- Improve integration of care around the patient, including the designation of a single authority to oversee healthcare delivery across the continuum of care (e.g., regional authorities or hospitals)
- Develop strategies to address the needs of the 5% of the population that accounts for 85% of healthcare costs

IV. Enhancing the Continuum of Care: Report of the Avoidable Hospitalization Advisory Panel ("Baker Report")

The Ministry of Health and Long-Term Care established the Avoidable Hospitalization Advisory Panel in September 2010 as part of the Excellent Healthcare for All Strategy (discussed below), to provide advice to government on how to reduce the number of avoidable readmissions to hospital. To accomplish their objectives, the Advisory Panel commissioned a literature review and jurisdictional scan on interventions to reduce readmissions, and analyzed Ontario's administrative data on readmissions. The Advisory Panel report outlines several recommendations that are relevant to the delivery of caregiver initiatives in the H&CC setting. These recommendations are as follows:

- Implement performance measures to reflect shared accountability for the broader system with consideration for local variation.
- Focus attention on high-risk, including social care needs of patients and families
- Strengthen HR in H&CC in order to improve transitions in care
- Strengthen CCAC and home care programs to include transition supports
- The MOHLTC should support the diffusion of best practice transition interventions across the province.

V. Caring for our Aging Population and Addressing Alternative Level of Care ("Walker Report")

In January 2011, the MOHLTC appointed Dr. David Walker as the Provincial Alternative Level of Care (ALC) lead. Dr. Walker was directed to make recommendations to address the causes of "Ontario's ALC challenge." The Report suggests that Ontario's healthcare system requires a "fundamental system redesign" that will shift resources out of institutional settings into the community, reform long-term care home programs, and hold primary care accountable for addressing the needs of individuals in the community. Several recommendations made in the report will be relevant for the delivery of caregiver support programs in the H&CC setting, including the following:

- Local Health Integration Networks (LHINs) should realign, refocus and enhance investments in the Community Support Services sector to support seniors and caregiver in the community, and to relieve the resource pressures on CCACs. Such investments would focus on homemaking services, caregiver support and respite services, and adult day programs for frail seniors and those with cognitive impairments.
- CCACs should further implement the "Home First" philosophy and resulting programs in a standardized, intensified, and prioritized manner.
- LHINs should invest in new models of care that provide opportunities for high-risk seniors or seniors with complex needs to be cared for in group home models.
- The MOHLTC should support the creation of special units / programs in the community and LTCHs for seniors with special needs. Targeted investments should focus on adding new human resources specialized in responsive and challenging behaviours in LTCHs, developing and deploying Mobile Behaviour Teams, and expanding services in the community.
- LHINs and CCACs should ensure that seniors are provided with timely Assess and Restore/Transitional Care in LTCHs while waiting for their first LTCH choice, in order for patients to have an opportunity to regain previous levels of function and to prevent deterioration.

VI. Ontario Government Action Plan for Health, 2012

In February 2012, the Ontario government released the Action Plan for Health, which outlines the

government's priorities for the healthcare system. Generally, these priorities focus on three areas:

- Keeping Ontario healthy
- Faster access to stronger family health care
- Right care, right time, right place.

Several priorities outlined in the Plan have implications for the H&CC sector. In particular, the Plan states that "The most significant part of our plan focuses on ensuring patients are receiving care in the most appropriate setting, wherever possible at home instead of in hospital or long-term care." This could mean increased emphasis on seniors' care and chronic disease management services in the community.

The Plan also suggests that this focus on community services will help address the challenges of ALC, which will free up hospital beds, reduce pressure on ERs, and save money. The Plan proposes a Seniors Strategy that will include a number of features:

- An expansion of house calls
- More access to home care through an additional 3 million PSW hours for seniors
- Care co-coordinators that will work closely with healthcare providers to make sure seniors are recovering after hospital stays to reduce readmissions.
- A Health Homes Renovation Tax Credit
- Greater flexibility for LHINs to shift resources to home and community care services.

VII. Key Initiatives

As mentioned earlier, a number of provincial initiatives have been implemented over the last several years that have had a direct or indirect impact on the delivery of H&CC services in Ontario. A common theme amongst these initiatives is the focus on reducing the utilization of acute care services (i.e., ER wait times and ALC days). The Caregiver Support Project will need to align itself with these priorities if it is to be successful and sustainable in the long-run. The following provides a brief summary of these key initiatives:

- **The Ontario Wait Times Strategy:** Addressing ALC is considered a key component of this strategy as reductions in ALC directly contribute to reductions in ER wait times. The initial ER Wait Times Strategy included funding for "home care services and enhanced integration between hospitals and the community."
- **Ageing at Home Strategy:** In August 2007, the government of Ontario launched a \$1.1 billion strategy to provide community living options for seniors. The strategy was implemented through the LHINs and was expected to relieve pressure on hospitals and long-term care homes by moving ALC patients to more appropriate settings.
- **Excellent Care for All Strategy (ECFA):** ECFA was announced in 2010 and includes four components: the Excellent Care for All Act, 2010; the expansion of the role of the Ontario Health Quality Council, Patient-Based Payment, and evidence-based practice. This strategy provides incentives to hospitals that achieve reductions in such areas as ALC days, lengths of stay, and readmissions. This includes incentives for hospitals to implement evidence-based discharge practices and establishing better linkages with the community.

The priorities of the Toronto Central LHIN follow this common theme as well. According to the Toronto Central LHINs 2010-2013 Integrated Health Services Plan, the LHINs top priorities are as follows:

- Reduce emergency room wait times and reduce ALC days.
- Improve the prevention, management and treatment of diabetes
- Improve prevention, management and treatment of mental illness and addiction
- Improve the value and affordability of health care services

Appendix B: Additional RAI-HC Analysis Results

This table compares TCCCAC RAI-HC data for all 1,554 clients in the TC SEC program and 91 clients in the CSP as of December 2011. This data reflects characteristics of seniors and their caregivers during the initial stages of the CSP. The results presented were not statistically significant at $p \leq 0.05$.

Characteristics	Label	Value	SEC		CSP		X ² p-Value
			N	%	N	%	
About the Senior							
Sex	Female	F	958	61.6	52	57.1	0.391
	Male	M	596	38.4	39	42.9	
CHES Scale	No Health Instability/Frailty	0	336	21.6	21	23.6	0.661
	Any Health Instability/Frailty	1+	1218	78.4	68	76.4	
Falls Frequency	None	0	965	62.1	60	67.4	0.314
	1 or more	1+	589	37.9	29	32.6	
Wandering	Yes	1 or 2	90	5.8	9	10	0.096
	No	0	1464	94.2	80	90	
Socially Disruptive Behaviour	Yes	1 or 2	36	2.3	4	4.5	0.195
	No	0	1518	97.7	85	95.5	
Resists Care	Yes	1 or 2	198	12.7	17	19.1	0.084
	No	0	1356	87.3	72	80.9	
Alzheimer's	Yes	1 or 2	235	15.1	17	18.7	0.360
	No	0	1319	84.9	74	81.3	
Mix of Formal and Informal Supports							
Service Utilization (hours)	0	0	208	13.6	10	11.2	0.852
	1-25	1-25	1143	74.8	67	75.3	
	26-50	26-50	98	6.4	5	5.6	
	51-75	51-75	28	1.8	3	3.4	
	75-100	75-100	9	0.6	1	1.1	
	100+	100+	42	2.7	3	3.4	
Area of Help: Advice/ Emotional	Yes	0	1493	97.8	89	100	0.155
	No	1	34	2.2	0	0	
Willingness to Increase ADL support	Willing	0 or 1	686	45.8	50	56.2	0.057
	Not Willing	2	811	54.2	39	43.8	
Caregiver Not Satisfied with Support From Family and Friends	Yes	1	103	6.6	8	9	0.388
	No	0	1451	93.4	81	91	

