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Caregiver Support Initiative: Formative Evaluation Preliminary Results

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We also wish to thank the twenty-five SEC case managers who participated in three expert panel sessions; their insights, energy and commitment add relevance and value to our findings.

1.0 Progress To-Date

The Balance of Care Research Group was commissioned to conduct a formative evaluation of the Alzheimer Society of Toronto's Caregiver Support Initiative. The initiative focuses on the vital role that families and caregivers play in providing care within the community for target populations, which include caregivers and care recipients at high risk or at the cusp of becoming high risk. This report presents a brief summary of our work to-date on the formative evaluation, including the results of a targeted review of the literature and caregiver initiatives, a preliminary analysis of RAI-HC Data, and the results of the first phase of our case manager expert panel focus groups.

Based on this work we can report the following preliminary findings:

- The literature suggests that more needs to be done to support caregivers who experience stress and burnout, as caregivers have a crucial role to play in supporting older persons, and in ensuring the sustainability and effectiveness of the healthcare system.
- However, the literature does not suggest a clear way in which caregiver initiatives should be designed. There is a general paucity of reliable evidence on the effectiveness of caregiver interventions and their impact on the health system. As a result, a wide variety of caregiver interventions have been implemented across Canada that have different specifications for the basket of services they provide, eligibility criteria and program administration.
- Preliminary findings from focus group sessions with case managers has revealed that they are positive about the impact of the caregiver support initiative and appreciate the flexibility it gives them in providing caregivers with the supports they need to carry on their caregiving activities.
- Preliminary findings also highlight some early implementation issues, including concerns about an unconstrained basket of services, the ability to isolate outcomes directly affected by the program, and the appropriate method of program administration.

In the following sections we present more details on these findings and the methods we used to obtain them.

1.1 Targeted Review of Caregiver Initiatives

We used mixed methods to conduct a review of the key dimensions of selected caregiver initiatives across Canada. The targeted review focused on the criteria programs used to target caregivers, the mix of services they provide, how these services are delivered, outcomes, and lessons learned. The targeted review included informal key informant interviews, and a review of the published and grey literatures.. Key informants were drawn from the following seven initiatives:

- Wesway – Family Directed Respite Program
- 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
- Victoria Order of Nurses – SMILE Program
- Family Service Toronto – Individualized Funding Program

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- Veterans Affairs - Veterans Independence Program (VIP)

Consultations were also conducted with key informants at the Ontario Caregiver Coalition

1.2 Analysis of Toronto Central RAI-HC Data

We conducted preliminary analysis of the TC CCAC Resident Assessment Instrument for Home Care (RAI-HC) data for individuals on the long-stay list, long-term care wait list, and in the Seniors Enhanced Care (SEC) Program. Participants for the caregiver support initiative were drawn from this SEC group.

We received the initial TC CCAC data set on September 13, 2011; this early data set did not identify participants in the caregiver support initiative. A second data set received on December 23, 2011 included all TC CCAC clients, and identified participants in the caregiver support initiative.

Preliminary analysis has been conducted on the initial data set (September, 2011) comparing the characteristics of caregivers and care recipients on the long-stay list, long-term care wait list, and in the SEC Program. Future analysis will compare the characteristics of those who did receive the caregiver support initiative to those who did not.

1.3 Expert Panel Sessions

We completed the first wave of expert panel sessions with three groups of SEC case managers (n=25). Expert panels were held on: October 31st, December 14th, and December 22nd, 2011. They aimed to document case managers' perspective in four key areas:

- Who – which caregivers have been selected to participate in the initiative and why
- What – the mix of cash, services and supports provided and why
- How – approaches to measuring and improving outcomes
- Challenges and opportunities associated with moving forward with the program

2.0 Preliminary Findings

2.1 Targeted Review of Caregiver Initiatives

As noted above, our targeted review included a scan of the published and grey literatures, as well as key informant interviews with individuals involved with other caregiver support initiatives. Our review of the literature highlighted the following key findings:

- There is a growing emphasis in the literature on the crucial role that caregivers play, not only in supporting the independence, quality of life and well-being of older persons, but also in contributing to health system sustainability.
- Indeed, from a policy perspective, there is a growing emphasis being placed on the importance of transitioning individuals from institutional settings to the home, and keeping them healthy in their homes for as long as possible. Several prominent and recent reports emphasize this point.¹

¹ Walker D. (2011). Caring for our aging population and addressing alternative level of care. Report Submitted to the Minister of Health and Long-Term Care; Avoidable Hospitalization Advisory Panel. (2011). Enhancing the Continuum of Care. Submitted to

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- However, there is very little evidence that highlights what works best in this context, particularly as it concerns the role of caregivers, and the supports they need to continue to carry out their role effectively. Formal evaluations of caregiver support initiatives are uncommon and those that have been completed (e.g., the Wesway Family Directed Respite Program, SMILE Program, and VIP) do not provide conclusive results with respect to program effectiveness.

Our discussions with key informants provided insight into the different approaches to caregiver support initiatives that have been implemented across Canada. These approaches include the following:

- **Respite** services that may involve direct services (e.g., home care) delivered to the care recipient or caregiver;
- **Community supports**, including services like transportation and housekeeping provided to the care recipient and/or caregiver;
- **Self-managed care**, where funds are provided directly to the caregiver so they can independently purchase health and social supports; and
- **Supported self-management**, where caregivers or care recipients receive funds to purchase services based on consultations with a case manager.

The key informant interviews also highlighted several important findings:

- There is no consistent approach to determining the mix of services that are provided to caregivers and care recipients. For example, the Nova Scotia Caregiver Benefit Program provides caregivers with a monthly payment to use in any way they see fit. In contrast, the Wesway Family Directed Respite Program and the VON SMILE Program both develop an individual care plan that outlines the specific services to be purchased.
- Respite and self-managed care are among the most common intervention types. However, there is great variability in program design. In particular, there is no consistent method of determining program eligibility, funding per client, or program administration. For instance, some programs have very general eligibility criteria, whereas other programs, such as, Nova Scotia Caregiver Benefit and the SMILE Program base their eligibility on more rigid criteria and standardized assessments (e.g., MAPLe scores).

2.2 RAI-HC Data

Our initial analysis of the RAI-HC data focused on two areas: 1) the characteristics of all informal caregivers who are providing care to individuals receiving long-term care services through the TC CCAC; and 2) the characteristics of informal caregivers who are categorized as "distressed". A caregiver is considered distressed if they are unable to continue their caring activities; and/or they experience feelings of distress, anger, or depression.

the Ministry of Health and Long-Term Care; Drummond D. (2011). Therapy or Surgery? A Prescription for Canada's Health System. C.D. Howe Institute.

Informal Caregiver Characteristics:

- Most (62%) of care recipients in the SEC program have live-in informal caregivers. The remaining care recipients have caregivers that live outside the home or do not have caregivers at all.
- The majority (57%) of SEC care recipients have a child, or child-in-law as their informal caregiver.
- A large majority (80%) of caregivers provide support with instrumental activities of daily living (IADLs) including meal preparation, housekeeping, phone use, and medication management. Fewer caregivers (about 40%) provide so-called "heavier care" supports for activities of daily living (ADLs), such as assisting with eating, personal hygiene, locomotion, and toilet use.
- Informal caregivers of care recipients in the SEC program spend about 22 hours during the week on caregiving activities. This is compared to 10 hours for caregivers of long-stay clients, and 16 hours for caregivers of wait-listed clients.

Informal Caregiver Distress:

- A minority (30%) of caregivers of care recipients in the SEC program experience feelings of distress. In fact, distress is highest for those caring for care recipients on the LTC wait-list.
- Overall, between 15% and 25% of all caregivers state that they are unable to continue in caregiving activities. However, 13.5% of the informal caregivers of care recipients in the SEC program are unable to continue caring activities.
- Most (73%) of care recipients in the SEC program and on the LTC wait-list have informal caregivers who are unwilling to increase the amount of ADL support they provide.
- Over 40% of care recipients who have very high needs have a caregiver who experiences distress.
- Many informal caregivers (40%) caring for an individual with moderate to very severe cognitive impairment are distressed.

3.1 Case Manager Expert Panel Focus Groups

As noted above, during the expert panel focus groups we asked SEC case managers to respond to four questions: how they selected caregiver/care recipient dyads to participate in the initiative, how they made decisions regarding the allocation of funds, how they would know if the caregiver initiative was successful, and if there were any challenges and opportunities with moving forward with the program. The following provides a summary of the key themes that surfaced during the focus group sessions.

3.1.1 Caregiver Selection

Several standardized criteria were established at the outset of the caregiver initiative and case managers were asked to follow these criteria when making decisions about the caregiver/care recipient dyads they were to select. These criteria are as follows:

- Caregiver consents to participation

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- Caregiver consents to using funds as agreed
- Care recipient and caregiver are seniors
 - Seniors are defined as persons age 55 and older. Exceptions are permitted where someone has prematurely aged due to an age-specific diagnosis, or drug/alcohol addiction.
- Caregiver is “primary” caregiver providing at least 10 or more hours per week
- Care recipient and caregiver live in TC LHIN
- Care recipient and/ or caregiver are at risk or caregiver is distressed.

During the focus group sessions, SEC case managers identified several additional considerations that they applied when selecting participants:

- Clients and caregivers who have limited family support
- Those experiencing cultural barriers-in particular language barriers
- Low income
- Those struggling with mental health problems
- Those who have recently experienced an acute episode
- Caregivers with paid employment
- Caregivers in frail health
- Caregivers in their role for longer than 6 months
- Caregivers at risk of entering long-term care or hospital

Case managers also emphasized that the 55+ age criteria may be too rigid as there are younger caregivers that also experience significant stress and would have been good candidates for the program.

3.1.2 Allocation Decisions

Case managers valued the flexibility they were given to work with caregivers to determine how resources could be used to best support the caregiver/care recipient dyad. For example, case managers provided resources via gift cards that allowed caregivers to purchase gas to cover transportation costs, or engage in self-care activities. Cash transfers were also used to purchase dental work, home equipment, and physiotherapy. Case managers were also able to arrange services to provide informal caregivers with respite in the form of extra PSW hours, which allowed caregivers to attend classes, exercise, or participate in community and religious activities. There are numerous other examples that were raised during the focus group sessions. The key point is that the initiative allowed case managers a great deal of flexibility in determining how to allocate services and that this led to a wide variety of interventions.

When asked about providing cash to caregivers -- similar to the Nova Scotia Caregiver Benefit -- case managers stated that, in their opinion, cash alone may not be the most appropriate solution for SEC clients and their caregivers. The case managers stressed that it was important that they engage in a guided conversation with the caregiver in order to determine what will really relieve the caregiver's stress. It was suggested that, without this, caregivers will have difficulty using the funds on themselves. Rather, they would choose to use the funds to address the care recipient's needs, pay bills, or for other activities that would shift the focus of the intervention away from the needs of the caregiver.

Case managers also expressed concerns that the funds could be abused, and/or make the dyad ineligible for other financial supports such as Ontario Works and Workplace Safety and Insurance Board (WSIB) benefits.

3.1.3 Measuring Outcomes

Care coordinators were asked how they would know if this pilot program was successful. The following suggestions were identified:

Maintaining current abilities: Care recipients are likely to decline as time goes on, and therefore, the stress placed on caregivers is likely to increase. Thus, case managers emphasized the importance of measuring caregivers' ability to maintain their current status-quo (level of assistance provided to care recipient, health status, etc.) rather than focus on improving their current situation.

Crisis applications: Case managers thought that a successful program would delay long-term care placement and reduce the amount of CCAC crisis applications. This program has the potential to prevent burnout, and therefore, avoid and/or reduce crisis applications to long-term care and ideally to allow care recipients to die at home if that is their goal.

Social, emotional and physical indicators: Case managers discussed using social, emotional and physical indicators before, during and after program implementation to determine success and/or failure. Case managers identified statements such as "I was able to sleep last night" and "I was able to shower and go to the bathroom alone" to be valid indicators of potential caregiver distress and burnout. Case managers identified that feelings of depression, sadness and frustration were triggers for long-term care placement. Avoiding such feelings would likely have an impact on the need for long-term care placement.

Assessment of coping: Case managers identified that they often do an 'off the books' assessment of coping. This involves asking, "how long do I anticipate that this caregiver will be able to cope successfully?". Case managers thought they could determine how long a caregiver is likely to cope prior to and after the completion of the project.

Caregiver burden scale: Case managers suggested that an assessment scale, such as the Caregiver Burden Scale, or something similar would be an effective and appropriate tool.

3.1.4 Challenges and Opportunities Moving Forward

Administration: This pilot project required a large amount of administration, including:

- communicating with case managers
- gathering and delivering services
- collecting and inputting data

Case managers emphasized that having access to funds and services immediately (thanks to administration staff) was extremely helpful and beneficial for both themselves and their client dyads.

Case manager time and workload: While the PST was thought to have been extremely beneficial for caregivers and their clients, the counseling process also increased the amount of time each case manager spends with the caregiver and care recipient. In addition, case managers noted that while in

the long run this project may reduce their workload (because clients in the program receive more services and therefore require less interaction with their case manager), it also requires considerable work up-front.

Flexibility, accountability and transparency: Participating case managers were asked to use a large amount of flexibility in their decision-making around which services to provide to caregivers. Future programs using a similar decision making method may benefit from using equally highly qualified case managers as well as clear justification for decision making and a built-in follow-up process.

System Savings: Case managers suggested caregiver support programs have the potential to lead to system savings in the long-term insofar as the program prevents crisis applications to LTC and utilization of healthcare services due to caregiver burnout.

Out of the box thinking: Case managers stated that a consistent challenge was helping caregivers focus on themselves and what services would help them cope. Most caregivers have difficulty with this as they are so used to thinking about the needs of the care recipient.

3.0 Next Steps

The following activities will be completed over the course of the remainder of the project (an overview of the data analysis plan is provided in Appendix A):

- In-depth analysis of the Toronto Central RAI-HC data including:
 - Long-stay clients
 - Wait listed clients
 - SEC program clients
 - Caregiver Support Initiative clients
- For all clients enrolled in the Caregiver Support Initiative, establish data linkages between Toronto Central RAI-HC data and the following project data collection tools:
 - Caregiver assessment surveys
 - Care plans (e.g. basket of services for each client)
 - One minute caregiver evaluations
- Additional analysis will be conducted comparing Hospital Emergency Department admissions for SEC clients and clients enrolled in the Caregiver Support Initiative, this data was included in the December 23rd, 2011 dataset for all current SEC clients and the 92 clients enrolled in the project to date.
- Wave two of expert panel sessions focusing on perceived outcomes for caregivers
- Develop strategies for collecting assessment data on new clients being enrolled in the Caregiver Support Initiative through Community Support Service (CSS) agencies. This may include application of the RAI-CHA or another unique assessment tool.
- Conduct expert panel sessions with new case workers recruited through CSS agencies

Appendix A: Data Analysis Plan

Caregiver Support Initiative (Alzheimer Society of Toronto)
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Data Sources and Linkages (revised December 13, 2011)

