

# Formative Evaluation of the Alzheimer Society of Toronto Counselling Program

## Final Report

Submitted to:  
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## **Executive Summary**

### **1.0 The Alzheimer Society of Toronto**

Under the umbrella of its Counselling Program (CP), the Alzheimer Society of Toronto (AST) offers a comprehensive suite of programs and services for caregivers and persons with Alzheimer's disease and other dementias (ADOD).

### **2.0 Formative Evaluation**

In September 2012, the *Balance of Care Research and Evaluation Group* at the University of Toronto (the "evaluation team") was commissioned by AST to conduct a formative evaluation of the CP. The formative evaluation considered the CP's main elements including:

- *One-on-one counselling*: in-person and over-the-phone therapeutic counselling to caregivers and persons with ADOD as well as consultation with health care professionals
- *Education workshops*: including workshops on disease progression and care strategies for caregivers and persons with dementia
- *Support groups*: tailored to the needs of caregivers and persons coping with specific types of dementia (e.g., frontotemporal dementia, lewy body dementia, and vascular dementia)
- *Creative therapy programs*: special programs and events such as *Art in the Moment: Art Gallery of Ontario Tours* and creative therapy sessions (e.g., *Drumming, Non-impact Aerobics* and *Dance Therapy*) offering additional opportunities for caregivers and persons with ADOD to engage with others in meaningful activities.

The evaluation also considered *First Link*, a collaboration between health care providers and Alzheimer Societies to ensure that persons with dementia and families are referred to specialized services as soon as possible after diagnosis. *First Link* was highlighted in the 2013 report by the Provincial Lead of the *Ontario Seniors Strategy*, which described it as "a vital support program and service for older adults and unpaid caregivers affected by dementia."

### **3.0 Findings**

#### **3.1 Environmental Scan**

Canadians are aging, and as they age they are more likely to live with multiple, chronic health and social needs (Government of Canada, 2002; Rocan, 2003; CIHI, 2011). This places new and unprecedented demands on health systems, which for the most part have been designed to provide curative medical care, on an episodic basis, in institutional settings such as hospitals and residential long-term care (e.g., nursing homes) (CIHI, 2011).

It also places growing, and sometimes unsustainable demands, on mostly unpaid, and untrained informal caregivers – spouses, children, family, friends and neighbours – who provide the bulk of the day-to-day instrumental and emotional support required by older persons to maintain their independence and well-being. Such demands are particularly challenging for caregivers of older persons with ADOD who may experience stress, fatigue, anxiety, guilt, social isolation, mental and physical illness, and burn-out.

The *Rising Tide* report estimates that about 2.8% of Canadians will have dementia by 2038 (Alzheimer Society of Canada, 2010). The cumulative economic cost of dementia is projected to be \$872 billion from 2008 to 2038 and there will be a 10-fold increase in demand for residential long-term care (Alzheimer Society of Canada, 2010). Caregiver burden will rise exponentially.

**Policy Context.** Recent policy statements and strategies emphasize the need to enhance community support options to reduce the likelihood that seniors will “default” to costly and often inappropriate hospital and residential LTC.

For example, *Ontario’s Seniors Strategy* (2013) argues for action to promote seniors’ wellness and support aging in place. It explicitly acknowledges the crucial role of informal caregivers in maintaining the well-being and independence of seniors in community settings, noting that caregiving can place “enormous toll on a caregiver’s health and well-being” and that more needs to be done “to support caregivers.”

Ontario’s new Health Links likewise focus on the needs of “high utilizers” including older persons with multiple chronic needs; Health Links emphasize the need to strengthen a continuum of community-based primary health care (including community supports) to reduce reliance on hospitals and LTC. While details are still to come, Health Links aim to provide “better and more quickly coordinated care”

**International Evidence.** A growing weight of international evidence confirms the worldwide growth of ADOD and the growing burden of care that will be experienced by informal caregivers. It also highlights a range of interventions, similar to those offered by the CP, that can help to moderate negative outcomes for caregivers and the health care system. These include individual and family counselling; psycho-educational programmes; specialized skills training on coping with challenging behaviors, managing sleep disruptions; multicomponent programmes that offer home visits, behavioural interventions, support groups, and provide access to local and community resources and services.

## **3.2 Counselling Program Data**

These data show continuing growth in hours and clients, and consistently positive outcomes.

### **One-on-one counselling**

- In 2011/12 AST provided over 4,100 hours of counselling which rose to over 5,000 hours in 2012/13, an increase of +23%
- Evaluation data from the AST/TC-CCAC (Toronto Central Community Care Access Centre) Inter-professional Collaboration project suggest that client confidence increased and stress declined.

### Education Workshops

- Between 2011/12 and 2012/13, total hours rose by more than half (+55%), as did numbers of clients (+54%)
- Evaluation data show that almost all participants felt that the workshops were a “good use of their time;” most “agreed” or “strongly agreed” that they gained valuable knowledge and understanding of Alzheimer’s disease; all agreed that their overall knowledge of Alzheimer’s disease had increased.

### Support Groups

- AST provided 123 hours of Support Groups in 2011/12; this rose to 143 hours in 2012/13, an increase of +16%. The number of clients in the support groups rose from 368 to 503, a 37% increase
- While limited, evaluation results suggest support groups were valued by participants and considered a “good use” of their time.

### Creative Therapy Programs

- AST provided 55.5 hours of creative therapy programs in 2011/12, and 70.5 hours in 2012/13, an increase of +27% (Table 5). The number of clients in creative therapy programs rose from 211 in 2011/12 to 281 in 2012/13, an increase of 33%.
- In evaluations of two workshops, participants highly rated their experience.

## 3.3 Client Perspectives

Clients identified strengths of the CP including:

- **AST is client-centred.** Services are personalized, friendly, welcoming, non-threatening, confidential, and emphasize relationship building.
- **The Counselling Program is a valuable support for caregiving.** Social workers were always available and worked with great flexibility to meet the needs of caregivers.
- **Support groups offer essential opportunities to build skills and connect with peers.** In addition to learning new skills (e.g., coping strategies, tax tips), support groups provided opportunities to share, listen and learn which “gave me hope” and “normalize[d] what was happening.”
- **The Alzheimer Society of Toronto website is a valuable first point of contact.** Shortly after their family member was diagnosed with dementia, clients searched for support for Alzheimer’s disease and other dementias on the internet.
- **The Counselling Program improved mental health for caregivers.** Participants stated that using the counselling services and attending support groups improved their overall mental health.

Clients perceived some challenges:

- **Location is an issue.** The high costs of transportation and parking when attending programs at the Eglinton office can stand in the way of clients who need to travel, often significant distances.
- **There are not enough spaces in support groups.** Some clients said they had to wait for months to participate in a support group of their choice. Aside from expanding support groups, waitlisted clients could be connected to volunteers to get support and normalize their feelings.
- **Other health care providers are not aware of AST.** Other health professionals and organizations did not seem to know or did not tell clients about AST.

### **3.4 Key Informant Perspectives**

Senior managers and staff identified multiple program strengths:

- **AST is unique.** AST provides a wide range of services and programs specifically for caregivers and person with ADOD. Clients are served at any point in the disease progression.
- **AST fills a crucial gap for people.** As the population ages, and more older persons and caregivers experience the debilitating effects of ADOD, AST provides vital counselling, peer support, education and skills development.
- **AST plays a vital system role.** AST fill gaps in dementia care in Toronto; support groups for specific dementias are not commonly available elsewhere. AST also connects clients to other providers and services (e.g., day programs, respite care).
- **AST is well positioned to lead dementia care into the future.** Areas of particular opportunity include education, service and technology.
- **AST and its clients gain from expanded collaborations with other agencies.** Initiatives such as *First Link* demonstrate the benefits of building collaborations with other providers to smooth referrals and lever capacity.

They also identified challenges:

- **Lack of awareness among people and providers.** In spite of best efforts, too few people and providers seem to know about AST and its CP.
- **Limited market reach.** AST currently reaches only a small proportion of caregivers and persons with ADOD in Toronto.
- **Funding is not secure.** Current funding comes from a mix of sources including government, corporations and individuals. While allowing AST considerable independence, this results in a cautious approach to growth opportunities.

- **Disconnects between the national Alzheimer Society, provincial offices and local chapters.** While there is extensive collegial interaction between local, provincial and national staff at the Toronto headquarters, there is no clearly elaborated framework or pathways for collaboration.
- **Geographic accessibility.** Although AST provides excellent services, in multiple locations, there are still groups of caregivers and persons with dementia that are underserved.
- **Perceptions of language and cultural barriers persist.** Although AST offers translation services and programming in different languages through community partners, key informants perceive that newer and emerging communities still do not have the services they require.
- **Insufficient staffing levels for greater outreach.** While there was a strong sense that AST could be doing more to connect with local communities, human resources limit significant expansion to satellite locations.
- **Not enough offerings for individuals at later stages of the disease progression.** Current programming tends to focus on persons in the early stages of dementia; persons with dementia at later stages need more attention.

### **3.5 Think Tank**

A number of consistent themes emerged.

- **Target caregivers and persons with ADOD early in the disease progression.** Early intervention, as soon as possible after diagnosis, gives greater scope to provide education, plan care and link to needed services before crisis occurs. AST should build on the success of its *First Link* program.
- **Coordinate, don't duplicate.** Advanced planning workshops, early onset dementia support groups and exercise programs for persons with dementia and their caregivers are examples of essential programs and services which aren't available elsewhere.
- **Strengthen outreach to increase awareness and access.** AST is currently operating more than ten satellite clinics across Toronto and there are also external education sessions for caregivers, persons with dementia and the general public. Nevertheless, participants said there is a need for greater outreach.
- **Expand use of e-technologies.** While persons with ADOD may not be able to make full use of e-technologies, many caregivers make extensive use of Google searches, trusted



web sites, and social media.

- **Establish new partnerships and build on existing partnerships.** In addition to strengthening existing partnerships with long-term agreements, consider establishing new partnerships with pharmaceutical companies, pharmacists and memory clinics.
- **Develop a registry for persons with dementia and their caregivers.** It was noted that Cancer Care Ontario operates a cancer registry which collects information from multiple sources including patient consultation and treatment records; a similar registry could be established for ADOD.

#### **4.0 Recommendations**

- **Recommendation 4.1. Build on the success of the CP.** The CP is strongly aligned with key research and policy directions; from multiple perspectives, it has achieved considerable success. Given the rising number of caregivers and persons with ADOD, and the growing challenges to health system sustainability, the CP should continue to expand.
- **Recommendation 4.2. Spread *First Link*.** *First Link* has been identified as an exemplar of what can and should be done across Ontario to respond to the growing needs of caregivers and persons with ADOD.
- **Recommendation 4.3. Engage in Health Links.** Through active engagement in Health Links, AST can increase awareness of the value of its CP. It can assist other professionals, providers and decision-makers to understand the needs and care trajectories of caregivers and persons with ADOD, who are already, or who may become, without appropriate community-based supports, high health care utilizers.
- **Recommendation 4.4. Create new partnerships and collaborations.** In addition to family health teams, community health centres, and community support agencies, future collaborations might include community-based providers who have regular “first-line” contact with caregivers and persons with ADOD including pharmacies and memory clinics. More partnerships with providers in diverse communities could ease barriers to access associated with language and culture.
- **Recommendation 4.5. Reach out to underserved communities.** While AST does not have the resources to offer and sustain a full range of services and programs in diverse communities on its own, it could use partnerships with other agencies to mount more workshops, support groups and creative therapy groups “in community spaces” where older persons of diverse cultures congregate, including supportive housing, nursing homes, home care facilities and retirement homes.

- **Recommendation 4.6. Make the most of e-technologies and e-learning.** More and more caregivers and persons with ADOD are web-savvy and use social media to educate themselves and find services. User-friendly web-based technologies could also be used to link providers, facilitate virtual inter-disciplinary teams, reduce travel time, encourage knowledge sharing, and smooth transitions. YouTube videos in different languages could increase awareness in diverse communities and link people to the CP.
- **Recommendation 4.7. Maximize the potential of the national Alzheimer Society infrastructure.** AST is one of a few community-based agencies with access to highly developed provincial and national infrastructures. Such infrastructures offer considerable potential to identify innovations and best practices in care for caregivers and persons with ADOD locally, provincially and nationally
- **Recommendation 4.8. Advocate for an Alzheimer’s strategy “from the ground up.”** Such a strategy could be assisted by the development of an ADOD registry similar to that used by Cancer Care Ontario, which, in addition to documenting numbers and characteristics of people, could help identify promising approaches to care.
- **Recommendation 4.9. Systematically document and disseminate the “facts” and the “faces” of the CP.** As the CP expands and evolves it is crucial to collect and analyze the numbers and characteristics of the people it serves, and outcomes at individual, organization and system levels. Standard intake protocol and client records, as well as ongoing assessment, are essential.

## ***Formative Evaluation of the Alzheimer Society of Toronto Counselling Program: Final Report***

### **1.0 The Alzheimer Society of Toronto**

Under the umbrella of its Counselling Program (CP), the Alzheimer Society of Toronto (AST) offers a comprehensive suite of programs and services for caregivers and persons with Alzheimer's disease and other dementias (ADOD). Since 1981, when AST was established, it has continuously expanded and evolved the CP to achieve its mission, role and vision (AST, 2013a).

**Mission:** To alleviate the personal and social consequences of Alzheimer's disease and related disorders and to promote research.

**Role:** To offer support, information and education to people with dementia, their families and their caregivers, to increase public awareness of dementia, to promote research, and to advocate for services that respect the dignity of the individual.

**Vision:** A world without Alzheimer's disease.

### **2.0 Formative Evaluation**

In September 2012, the Balance of Care Research and Evaluation Group at the University of Toronto (the "evaluation team") was commissioned by AST to conduct a formative evaluation of its CP. Objectives were to:

- Improve design and operation through internal transformation as needed
- Demonstrate value to external stakeholders including consumers, current and potential funders and policy-makers.

In doing this, the formative evaluation was to consider the CP's main elements including:

- ***One-on-one counselling.*** AST offers in-person and over-the-phone therapeutic counselling to caregivers and persons with ADOD. Counselling is provided by qualified social workers. It covers a wide range of issues including getting a diagnosis, coping, grief, and future planning. Social workers provide intensive interventions for as long as needed, including post-placement in long-term care (LTC) and following the death of the person with dementia.
- ***Education workshops.*** Through its social workers and public educational coordinators (PECs), AST offers a range of education workshops about ADOD, disease progression, and care strategies, to caregivers and persons with dementia. Workshops are offered at a number of different locations, often in partnership with other organizations using a variety of media (e.g., on-line modules, webinars).
- ***Support groups.*** AST offers support groups tailored to the needs of persons coping with specific types of dementia (e.g., frontotemporal dementia, lewy body dementia,

and vascular dementia). The focus is on learning from other individuals facing similar situations and collectively building coping strategies. In addition, AST runs the *Support Group Leader Network* which provides education, resources and consultation for leaders of support programs offered by other organizations.

- ***Creative therapy programs.*** Special programs and events such as *Art in the Moment: Art Gallery of Ontario* tours and creative therapy sessions (e.g., *Drumming, Non-impact Aerobics* and *Dance Therapy*) offer additional opportunities for caregivers and persons with ADOD to engage with others in meaningful activities and open new pathways of understanding and communication.

The evaluation also considered *First Link*, a collaboration between health care providers and Alzheimer Societies to ensure that persons with dementia and families are referred to specialized services as soon as possible after diagnosis. *First Link* was recently highlighted in the 2013 report by the Provincial Lead of the *Ontario Seniors Strategy*, which described it as “a vital support program and service for older adults and unpaid caregivers affected by dementia.” The report recommended that it be made “available to all” through “implementation of this program in every LHIN across Ontario” (Sinha, 2013: 16). While a full review of *First Link* was beyond the scope of this evaluation, we report highlights of an evaluation of the *First Link Demonstration Project* (2007-2009) conducted in 2010 which demonstrated that, as a result of their participation, persons with dementia and caregivers were more knowledgeable about dementia and more confident in their ability to cope.

## **2.1 Formative Evaluation Design Considerations**

In contrast to conventional outcomes evaluation which aims to measure specific outcomes of a particular intervention, for specific individuals, in a specific context, formative evaluation looks more broadly at a range of variables and factors related to structure and process, impacting on a range of qualitative and quantitative outcomes at individual (micro), organization (meso) and system (macro) levels.

Our choice of formative evaluation considered the following:

- ***The CP is broad in scope.*** As noted, rather than constituting a single entity, the CP is an umbrella for a suite of individual programs and services to support caregivers and persons with dementia.
- ***There are multiple stakeholders.*** In addition to addressing the needs of persons with ADOD, the CP aims to benefit other stakeholders including informal caregivers (e.g., family, friends and neighbours); formal care providers (e.g., paid workers, professionals and provider organizations); and the health care system.
- ***Outcomes are both quantitative and qualitative.*** The literature suggests that as a result of different support interventions, persons with ADOD may experience an enhanced ability to adapt to life changes, and higher quality of life. For caregivers, outcomes may

include improved knowledge of Alzheimer's disease, better coping strategies, greater confidence and satisfaction, and lower stress. Providers may benefit from more effective, collaborative approaches to client care. Health systems may experience more moderate demand for costly, and sometimes avoidable, hospital and institutional care.

- *Evaluation should not unnecessarily burden caregivers and persons with ADOD.* Caregivers and persons with ADOD are at the very core of AST's mission and vision; evaluation should record their voice. However, even if unintended, evaluation can add burden and stress by requiring time and energy, or by touching on sensitive issues. Evaluation can also create anxiety if clients fear that negative responses could compromise access to vital supports. We therefore aimed to make the best use of existing data, supplemented, when appropriate, by targeted interviews and focus groups with self-selected clients who volunteered to participate in the evaluation.
- *The CP is situated in a complex and volatile environment.* The CP takes place in a context of "continuous white water." Not only are the needs of caregivers and persons with ADOD growing and evolving, there is massive, rapid change in the research and policy environments in which the CP takes place. In addition to considering historical performance, evaluation must look toward the horizon.

## **2.2 Evaluation Components**

The evaluation was conducted between September 2012 and March 2013. As detailed in the sections below, it incorporates multiple data sources and methods.

### ***2.2.1 Environmental Scan***

We conducted a high level scan of the research evidence and policy context for the CP, aimed at identifying factors impacting on its past performance, and its future path.

For example, we considered highlights of the growing published and grey literatures around persons with ADOD, including data which show that both numbers and economic impact continue to grow, placing new demands on formal care systems, and on informal caregivers.

Our scan also looked at a number of recent policy reports and strategies potentially impacting on caregivers and persons with ADOD, as well as on agencies, like AST, aiming to serve growing needs at the local level. Among the documents we considered:

- Ontario's *Strategy for Alzheimer Disease and Related Dementias* (1994-2004)
- Ontario's *Caring-About-Caregivers Long-Range Scenario Planning* (2008)
- *The Rising Tide* (2010)
- The "Walker" Report: *Caring for Our Aging Population and Addressing Alternate Level of Care* (2011)
- The "Drummond" Report: *Commission on the Reform of Ontario's Public Services* (2012)
- *Ontario's Action Plan for Health Care* (2012)

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- The “Sinha” Report: *Living Longer, Living Well: Highlights and Key Recommendations* (2013)
- *Ontario’s Action Plan for Seniors* (2013)
- Health Links (2013)

We also considered influential reports and strategies from other jurisdictions including:

- The Shriver Report: *A Woman’s Nation Changes Everything* (2009)
- The Shriver Report : *A Woman’s Nation Takes on Alzheimer’s* (2010)
- The World Health Organization (WHO) report: *Dementia: A Public Health Priority* (2012)
- Women and Alzheimer's Disease: *The Caregiver's Crisis* (2012).

Finally, we conducted a rapid review of the literature on interventions for caregivers and persons with ADOD. While there is much literature on the “rising tide” of Alzheimer’s disease and other dementias, and many proposed strategies and interventions for addressing needs, there is relatively little systematic evidence demonstrating outcomes or cost-effectiveness.

Nevertheless, we considered a number of frequently cited research articles examining:

- The outcomes of individual and family counselling (e.g., Mittleman et al., 1993, 1994, 2007, 2008)
- The outcomes of specialized skills training (e.g., Teri et al., 1997, 2005; Farran et al. 2004; Gonyea et al., 2006; and Gitlin et al., 2008).

### ***2.2.2 Analysis of CP Data***

With the assistance of AST staff, we accessed and analyzed accessible (in electronic format) CP data measuring client numbers and characteristics for one-on-one counselling, education workshops, support groups, and creative therapy programs.

We also reviewed information detailing the historical evolution of AST, as well as the rationale, objectives, target audiences and evaluation findings for each of the four program areas. This included results from an evaluation of a collaborative project with the Toronto Central Community Care Access Centre (TC CCAC), as well as the *AST Strategic Planning Retreat* summary (2012), and the *AST 2012/13 Year End Report*.

### ***2.2.3 Client Perspectives***

To help us better understand client perspectives, we conducted focus groups and individual interviews with self-selected CP clients.

To minimize any real or perceived risk, evaluation team members did not contact clients directly; rather, AST staff extended a general invitation to clients to participate and then provided dates and contact information for the evaluation team.

To facilitate access and a familiar setting, focus groups were conducted at AST offices. To reassure clients that their views would remain anonymous, focus groups were not audio-recorded; rather, pairs of team members took detailed field notes, and cross-checked notes for accuracy during analysis. Focus groups lasted about 90 minutes.

The focus group “script” was developed in consultation with AST staff. Participants were asked:

- How did you find out about AST?
- What programs and services did you use?
- What do you like most? Least?
- Have the programs and services you used benefited you? How?
- What changes (if any) would you recommend?

A total of 8 clients (all caregivers) participated in two focus groups. An additional 3 clients (also caregivers) were interviewed by telephone using the focus group questions.

### ***2.2.4 Key Informant Perspectives***

We also conducted 14 semi-structured, in-depth, qualitative interviews with “key informants,” individuals with first-hand knowledge of the CP who could provide informed insight on its current opportunities and challenges, and future potential.

Within AST, key informants included members of the senior management team, social workers, PECs, and the First Link Coordinator. Interviews were conducted by telephone or in-person by pairs of evaluation team members; they averaged about 45 minutes, with some lasting 90 minutes. Detailed field notes were recorded by both interviewers and then cross-checked during analysis.

Interviewees were asked combinations of the following questions:

- What makes the Alzheimer Society of Toronto unique?
- What are the strengths of the Counselling Program?
- How well does the Counselling Program serve:
  - Caregivers?
  - Persons with dementia?
  - Underserved populations?
  - The health care system?
- What are some of the challenges, opportunities and areas of improvements?
- To what extent does the Counselling Program foster collaboration with key providers, consumers and policymakers?
- Where do you envision the organization in 10 years?

### ***2.2.5 Think Tank***

We also conducted a half-day Think Tank at AST offices with key external stakeholders. Think Tank participants included representatives of the following organizations:

- Alzheimer Society of Canada
- Alzheimer Society of Ontario
- Alzheimer Society of Toronto
- Anne Johnston Health Station
- CareFirst Seniors and Community Services Association



- Circle of Care
- Family Service Toronto
- Ontario Community Support Association
- Saint Elizabeth Health Care
- SPRINT
- St. Clair West Services for Seniors
- Toronto Central CCAC
- Toronto Central LHIN
- TransCare Community Support Services
- Yee Hong Centre for Geriatric Care

Participants were assigned to small groups facilitated by evaluation team members. “Real time” interaction was enabled through a live Twitter feed. With respect to the CP, participants were asked:

- Who should be targeted?
- How should the mix of programs and services be balanced?
- How can delivery and reach be strengthened?

We also asked participants to help build a “business case” for the CP. We asked:

- What are the essential elements of a business case?
- What benefits does [the CP] offer (e.g., caregiver resilience, moderated use of hospital and institutional care, improved care integration)?
- What internal resources (including expertise, credibility, infrastructure) does [the CP] bring to the table?
- What will be required to achieve sustainability?
- Why is this a good investment for public or private investors?

The evaluation team then assessed the recorded Twitter feed for recurrent themes.



## **3.0 Findings**

### **3.1 Context**

It is by now widely acknowledged that Canadians are aging, and as they age, are more likely to live with multiple chronic health and social needs in the community (Government of Canada, 2002; Rocan, 2003; CIHI, 2011). This places new and unprecedented demands on health care systems, which for the most part have been designed to provide curative medical care, on an episodic basis, in institutional settings such as hospitals and residential LTC (e.g., nursing homes) (CIHI, 2011).

It also places growing, and sometimes unsustainable demands, on mostly unpaid and untrained informal caregivers – spouses, children, family, friends and neighbours – who provide the bulk of the day-to-day instrumental and emotional support required by older persons to maintain their independence and well-being.

Such demands are particularly challenging for caregivers of older persons with ADOD who may experience stress, fatigue, anxiety, guilt, social isolation, mental and physical illness, and burnout.

The following composite vignette is based on our client focus groups and interviews; it illustrates a typical caregiver of an older person with ADOD.

#### **Introducing Mary**

- When Mary's mother was first diagnosed with Alzheimer's disease, she knew very little about the disease and what it would mean for her mother and herself
- Mary felt very alone – she felt like there wasn't anyone else that understood what she was experiencing
- Mary was having trouble dealing with her negative emotions towards her mother – she felt guilty
- Mary "didn't know where to turn" for help and worried that she wouldn't be able to care for her mother.

There are many more Marys. The *Rising Tide* report estimates that about 2.8% of Canadians will have dementia by 2038 (Alzheimer Society of Canada, 2010). The cumulative economic cost of dementia is projected to be \$872 billion from 2008 to 2038 and there will be a 10-fold increase in demand for residential long-term care (Alzheimer Society of Canada, 2010). Caregiver burden will rise exponentially.

While very personal, Mary's experiences, and those of all the other caregivers of older persons with ADOD, have broader impact. Put bluntly, if Mary and other caregivers fail, an already stretched formal health care system will bear the cost.

### 3.1.1 Policy Context

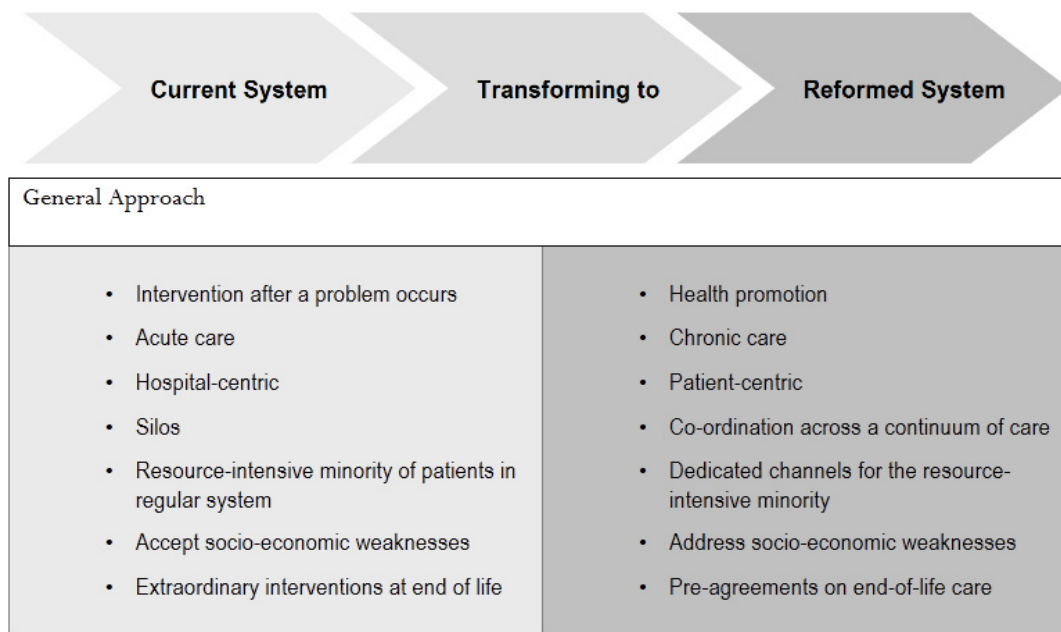
*Ontario’s Action Plan for Seniors (2013) highlights the system-level challenges that make it all the more important to find ways to support Mary and her mother.*

*“The top 10 per cent of Ontario’s older population, characterized as having the most complex issues, accounts for 60 per cent of the total annual health care spending for this population ...*

*Today, seniors account for nearly half of Ontario’s health care spending. By 2030, if we don’t make changes to the way we deliver health care services, the increased number of seniors in the province is projected to cost \$24 billion more annually – that is 50 per cent more than today” (Government of Ontario, 2013; 5).*

When systems fail to provide needed prevention/maintenance supports in the community, there is a greater likelihood that Mary and her mother will “default” to costly hospital and residential LTC (Walker, 2011: 6). As Walker noted, current care models rely too heavily on acute care hospitals and “permanent” placement for seniors after the fact (Walker, 2011: 6). He argues that greater efforts should be made to keep people out of hospitals and residential LTC in the first place.





The highly influential report of the *Commission on the Reform of Ontario’s Public Services* (Drummond, 2012) takes a similar perspective. After characterizing the current health care system as a high cost, non-system of fragmented services and providers, Drummond makes numerous recommendations for change, including many emphasizing the need to bolster community-based primary and preventive care, especially for persons with complex, continuing needs. The figure below summarizes Drummond’s high level recommendations.



Source: Drummond, 2012: 168

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*Ontario's Seniors Strategy* (2013) reinforces these themes. As summarized in the figure below, Sinha argues for action to promote seniors' wellness and to support aging in place, and, when this is no longer an option, to make hospitals and LTC more "friendly" to seniors. He explicitly acknowledges the crucial role of informal caregivers in maintaining the well-being and independence of seniors in community settings, noting that caregiving can place "enormous toll on a caregiver's health and well-being" and that more needs to be done "to support caregivers" (Sinha, 2013: 21).

Promoting Wellness	Supporting Aging in Place	Senior Friendly Hospital Care and Effective Transitions	Enhanced Long-Term Care Environments
 <p>-Single point of access to information to empower and support self-management</p> <p>-Wellness and prevention programs will reduce de-conditioning, improve functional capacity, independence and older adults ability to stay home longer:</p> <p>-Leverage Elderly Persons Centres to help strengthen social networks and provide access to wellness and prevention and care services.</p> <p>-Promote screening and early linkage to the appropriate support services</p>	 <p>-Strengthened Primary Care models will improve access and provide home-based care options.</p> <p>-Enhanced CCAC and CSS Services and linkages to Primary Care.</p> <p>-Improve access to community-based therapy services that optimize functional capacity and independence</p> <p>-Telehomecare, NLOTs and Geriatric Services.</p>	 <p>-When hospital care is required, seniors will benefit from an elder friendly environment and culture emphasizing early screening and assessment by GEM Nurses, functional support and timely discharge home/community and the prevention of ALC.</p> <p>-Seamless and Safe discharges facilitated by Rapid Response Nurses emphasizing a connection to the primary care provider within 7 days of discharge.</p>	 <p>-Improving the capacity of the long-term care sector to support more short-stay and restorative care options and discharge back to the community</p> <p>-Specialized services for residents with challenging and complex behaviours</p> <p>-Quality long-term care for residents who require it</p> <p>-Reduced ED/hospital transfers through enhanced NLOT services.</p>

Source: Sinha, 2012

Ontario's recently announced Health Links likewise focus on the needs of "high utilizers" including older persons with multiple chronic needs; Health Links emphasize the need to strengthen a continuum of community-based primary health care (including community supports) to reduce reliance on hospitals and LTC. While details are still to come, Health Links aim to provide "better and more quickly coordinated care" (MOHLTC, 2012). As a result, older persons and caregivers requiring multiple services from multiple providers will:

- "No longer need to answer the same question from different providers
- Have support to ensure they are taking the right medications appropriately
- Have a care provider they can call, eliminating unnecessary provider visits
- Have an individualized comprehensive plan, developed with the patient and his/her care providers who will ensure the plan is being followed" (MOHLTC, 2012).

Such strategies add new impetus to initiatives to fill current gaps in community-based care; for caregivers and persons with ADOD, these gaps are particularly large.

For example, Ontario does not currently have an Alzheimer's strategy; Canada has never had one. In the late 1990's the Ontario government launched a strategy to address the rise of

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Alzheimer's disease and other dementias called *Preparing for Our Future (1999)*; even 20 years ago it was recognized that the number of persons with ADOD would continue to grow, and that new investments would need to be made to moderate the impact on people and system. The *Strategy* promised investments of \$68.4 million to "better meet the needs" of people with Alzheimer's disease and other dementias and their caregivers (MOHLTC, 1999). Among its list of actions, the *Strategy* promised \$3 million initially and an additional \$7 million per annum starting in 2000/2001 for respite services for caregivers. In addition, \$0.5 million was to be invested in research on caregiver needs (MOHLTC, 1999). However, the *Strategy* effectively ended in 2004.

Nor does Ontario have a caregivers strategy. In 2009, Ontario engaged in a wide-ranging set of public consultations involving health care leaders, experts, researchers and caregivers, resulting in its *Caring-About-Caregivers Long-Range Scenario Planning (LRSP)* document (MOHLTC, 2009). The LRSP aimed to find ways to better support family and other informal caregivers even as caregiver burden grows, and as caregiving declines, suggesting new and possibly unsustainable demands on the formal care system. The LRSP emphasized the need for:

- More expansive definitions of caregiving
- New supports for caregivers in new economic and demographic contexts
- Better system navigation tools and caregiver education
- Measures to build sustainable social support networks.

However, with the exception of more favorable work-leave legislation, which allows caregivers unpaid time-off from their jobs, little more has happened at the provincial level.

Of course, the landscape is not all bleak; there are new local initiatives to assist caregivers and persons with high needs. For example, the Toronto Central LHIN now funds two caregiver support initiatives, including one led by AST.

- The first, initiated and administered by AST in collaboration with the TC CCAC and seven community support agencies, aims to support "at risk" informal caregivers of "high needs" older persons at the verge of institutionalization
- The second, led by the Hospital for Sick Children, in collaboration with the TC CCAC and Holland Bloorview Children's Hospital, supports "at risk" caregivers of children with complex, continuing medical needs.

While these initiatives have not yet been fully evaluated, they suggest growing interest in action to maintain high needs persons and caregivers in community settings, both in their interests, and as a means of moderating demand for hospital and institutional care.

### ***3.1.2 International Evidence***

Such action is also supported by a growing weight of international evidence documenting the rise of ADOD and the costs and consequences for informal caregivers.

For example, *Dementia: A Public Health Priority* (World Health Organization, 2012) provides in-depth discussion of the epidemiology of dementia; dementia policy and ethical issues;

dementia health and social care systems; dementia caregiving and caregivers; and public understanding of dementia (WHO, 2012). It observes (critically) that in spite of documented and growing need, only a handful of industrialized countries (excluding Canada) have a national dementia strategy.

*Women and Alzheimer's Disease: The Caregiver's Crisis*, produced by a public policy think tank in the US (Working Mother Research Institute, 2012), documents the rising burden of care for persons with Alzheimer's disease. It demonstrates how caregivers' emotional health, financial security, employment and family lives can be negatively impacted by caregiving responsibilities. It notes that caregivers, particularly females, are often stuck in a caregiving role, and that many, particularly those from minority groups, struggle "in every area of life" as a result.

The "Shriver Report," *A Woman's Nation Takes on Alzheimer's* (2010) underscores the fact that women are more likely than men to live with dementia, and that when they do, the majority of care they receive is from other women. It observes that:

- One-third of female caregivers are caring for a person with Alzheimer's disease 24/7
- The societal impact of Alzheimer's disease on the government, families and business is calculated to be about \$300 billion per year
- About two of three working caregivers reported arriving to work late, leaving early or taking time off to provide care and support for someone with Alzheimer's disease.

Such evidence emphasizes that although the rise of dementia may be a "natural" consequence of an aging population, the resulting burden of care is not equally distributed across society, and that such burden may be deepened by public policies which encourage care in home and community, but fail to provide essential supports.

A recent report by the Conference Board of Canada (2012: 28) neatly captures this point. It states that:

"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 ...

A further shift toward care in the home ... means an even greater reliance on unpaid caregivers."

### ***3.1.3 Counting the Costs***

The research literature further elaborates the impact on informal caregivers.

It shows, for example, that caregivers can experience multiple stressors when caring for persons with ADOD. Primary stressors include time spent caring, and the variety and intensity of the behavioural, cognitive and psychological symptoms that they face daily (WHO, 2012). Secondary stressors include role strains from competing demands and family conflicts (WHO, 2012). In addition, the specific clinical features of dementia, such as aggressive or challenging behaviors, were also identified as contributing to caregiver strain.

Such stressors can negatively impact caregivers' health, quality of life and financial security. Studies have found that compared to non-caregivers, caregivers can experience higher levels of perceived stress and depression, and lower self-efficacy (Pinquart & Sorensen, 2003). Caregivers may have weaker immune systems than non-caregivers, increasing their susceptibility to illness and disease (Kiecolt-Glaser *et al.*, 1987). Caregivers are more likely to over-use and abuse substances (e.g., alcohol) and they are more vulnerable to emotional symptoms and disorders such as anxiety, grief, guilt and rage (Sadavoy, 2011). Caregivers of persons with ADOD experience physical and mental health challenges including depression (Pinquart & Sorensen, 2003; Pinquart & Sorensen, 2006).

Informal caregivers can also incur significant economic costs. Research has found that at least one of three caregivers paid out-of-pocket expenses (Cranswick, 2003) and about two out of three Canadian caregivers contributed more than \$100 per month (Decima Research Inc., 2002). Examples of the out-of-pocket expenses include the purchase of goods and services (e.g., medical equipment) and travel costs (Cranswick, 2003). In addition, caregivers may not be able to participate fully in paid work (Canadian Association for Community Living & Canadian Caregiver Coalition, 2003), impacting on current economic status, future career prospects, and pension benefits (Canadian Association for Community Living & Canadian Caregiver Coalition, 2003).

### ***3.1.4 Supporting Caregivers***

There is, therefore, a growing consensus in the research and policy literatures, around the need to support caregivers. Different countries have introduced a range of caregiver supports including caregiver allowances; favourable labour policies; support services; and counselling and education, albeit with widely varying benefits and eligibility requirements.

A number of studies point to the efficacy of interventions including individual and family counselling, psycho-educational programmes, specialized skills training, multicomponent programmes, and psychotherapy/cognitive behavioural therapy (WHO, 2012).

For example, research findings suggest that:

- Individual and family counselling for spouse-caregivers can delay the institutionalization of Alzheimer's patients to long-term care facilities (Mittelman *et al.*, 1993; Mittelman *et*



*al.*, 1996). Counselling can also improve caregiver health (Mittelman *et al.*, 2007) and reduce caregiver depression (Mittelman *et al.*, 2004; Mittelman *et al.*, 2008)

- Psycho-educational programmes can improve the quality of life of people living with Alzheimer's and their caregivers (Olazaran *et al.*, 2010). Such programmes can also delay institutionalization (Sorensen *et al.*, 2006), reduce caregiver distress (Sorensen *et al.*, 2006; Gallagher-Thompson & Coon, 2007) and improve caregiver well-being (Gallagher-Thompson & Coon, 2007)
- Specialized skills training on coping with challenging behaviors, managing sleep disruptions and promoting exercise for stress relief can significantly improve caregivers' depression symptoms (Teri *et al.*, 1997; Farran *et al.*, 2004) and significantly reduce caregiver distress and burden (Teri *et al.*, 2005; Gonyea *et al.*, 2006; Gitlin *et al.*, 2008).
- Multicomponent programmes that offer home visits, behavioural interventions, support groups, and provide access to local and community resources and services can significantly improve caregivers' quality of life (Belle *et al.*, 2006) and postpone institutionalization of people with dementia (Brodaty *et al.*, 1997).
- Psychotherapy/cognitive behavioural therapy is effective for caregivers with depression or significant mental health problems; the number of caregivers who were clinically depressed decreased after therapy (Gallagher-Thompson & Steffen, 1994).
- Exercise can be an effective and low cost means of preventing and managing ADOD. According to a recent study, older adults without Alzheimer's disease (aged 60 to 80) exhibited a 2% volume increase in their hippocampus, an important region for memory, after walking moderately for 30 to 45 minutes three days a week for a year (Erickson, 2012). Similarly, the results of a randomized, controlled trial showed that an exercise program (1 hour, twice a week of walk, strength, balance, and flexibility training) significantly slowed the decline in performing activities of daily living (ADLs) for patients with Alzheimer's disease living in a nursing home (P=0.02) (Rolland *et al.*, 2007).

### **3.1.5 First Link**

The policy literature also describes a number of "promising practices," interventions which, although not yet fully evaluated, seem to offer benefits to older persons with ADOD, caregivers, and the health care system.

One such promising practice is *First Link*, a collaborative program between health care providers and Alzheimer Societies to ensure that persons with dementia and families are referred to specialized services as soon as possible after diagnosis.

As noted earlier, evaluation of the *First Link Demonstration Project* (2007-2009) revealed that persons with dementia and their caregivers were more knowledgeable about dementia and more confident in their ability to cope (McAiney *et al.*, 2010).

*“Having the First Link intake worker contact me was like a shot in the arm and I look forward to drawing strengths from the program as our situation changes, as it no doubt will as the disease progresses” (McAiney et al., 2010).*

For healthcare professionals, the referral process was “extremely easy, efficient and seamless” (McAiney et al., 2010).

*“Every effort should be made to continue First Link programs as they are just excellent for providing security and hope to individuals and families who are “groping in the dark” to come to grips with the uncertainties as they affect both caregivers and patients at the time Alzheimer’s/dementia has been diagnosed” (McAiney et al., 2010).*

Recognizing the potential of *First Link*, Ontario’s *Seniors Strategy* states that “the Ministry of Health and Long-Term Care should encourage the standardization of services and supports offered through the Alzheimer Society’s *First Link* program and fully support the implementation of this program in every LHIN across Ontario.” The *First Link* program should be “available to all” (Sinha, 2013: 21).

## **3.2 Counselling Program Data**

The evaluation team assessed program data provided by AST which describe key characteristics of elements of the CP, show utilization trends, and record feedback from clients and staff.

### ***3.2.1 One-on-one Counselling***

A key component of the CP is one-on-one counselling for caregivers and persons with ADOD. According to AST documentations, this intensive, therapeutic counselling covers a wide range of issues including “getting a diagnosis, understanding dementia, immediate and future care, family concerns, and coping strategies” (AST, 2013b). Inclusivity, confidentiality and relationship-building are presented as core values.

Counselling is provided by qualified social workers with extensive knowledge, training and experience in dementia, dementia care and caregiving issues. Clients are assessed at point-of-entry and social workers may use different approaches including Mindfulness, Cognitive Behavioural Therapy (CBT) and Problem Solving Therapy (PST).

Language interpreter services are available over the telephone. Therapeutic counselling spans office visits, home visits and telephone calls and it is free of charge (AST, 2013c). AST also offers satellite clinics at various community agencies including SPRINT (Senior Peoples’ Resources in North Toronto), Etobicoke Services for Seniors, St. Clair West Services for Seniors, Providence Healthcare, Scarborough Centre for Healthy Communities, Casey House, and The 519 Church Street Community Centre.

One-on-one counselling is provided on an ongoing basis to people with dementia and their families. This can span years, both prior to and post diagnosis, through admission to residential



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LTC, and even after the death of the person with dementia. Stated benefits of counselling include (AST 2013d):

- Learning about practical suggestions and strategies, which may help you to better understand and cope with your own or a family member's dementia symptoms, and plan for the future
- Strategies around behaviours
- Discussing personal circumstances and feelings that you might be experiencing
- Learning about community resources, such as support groups and adult day programs.

**Program data.** As shown in Table 1, AST provided over 4,100 hours of counselling in 2011/12 and over 5,000 hours in 2012/13, an increase of +23% (AST, 2013e). While numbers of new clients contacting AST directly during this period remained more or less constant, there were more existing clients who received subsequent visits (AST, 2013e).

<b>Table 1. Intake data, one-on-one counselling, 2011/12 and 2012/13</b>			
	<b>2011/12</b>	<b>2012/13</b>	<b>% change</b>
<b>Total hours of counselling</b>	4,106	5,030	+23%
<b>Number of new clients who contact AST (including First Link)</b>	3,159	3,434	+9%
<b>Subsequent contacts with clients</b>	3,260	4,425	+36%

Source: AST, 2013e

**Outcomes.** Outcomes data for counselling is limited; nevertheless, findings from the related AST/TC-CCAC (Toronto Central Community Care Access Centre) Inter-professional Collaboration project suggest a positive impact.

In the collaborative project, TC-CCAC Seniors' Enhanced Care (SEC) care coordinators refer caregivers of high needs older persons to AST where AST social workers then assess needs and arrange necessary supports and services (AST, 2012a). The project aims to:

- Improve services to CCAC clients
- Develop and enhance the knowledge and skills of care coordinators
- Improve quality of care and prevent or reduce family crises that may lead to inappropriate ER visits, extended stays in ALC and premature placement in long-term care facilities (AST, 2012a).

Evaluation findings show that:

- Between January, 2012 and December, 2012, the project recorded 670 new contacts; of these, about 60% (395 contacts) received counselling, mostly by telephone (AST, 2012b)
- A total of 681 issues were raised by spouses and children. While spouses were more likely to discuss assistance at home and health concerns, adult children were more

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interested in caregiving strategies and management of caregiver stress. Spouses and adult children both received advice around behavior management (AST, 2012b)

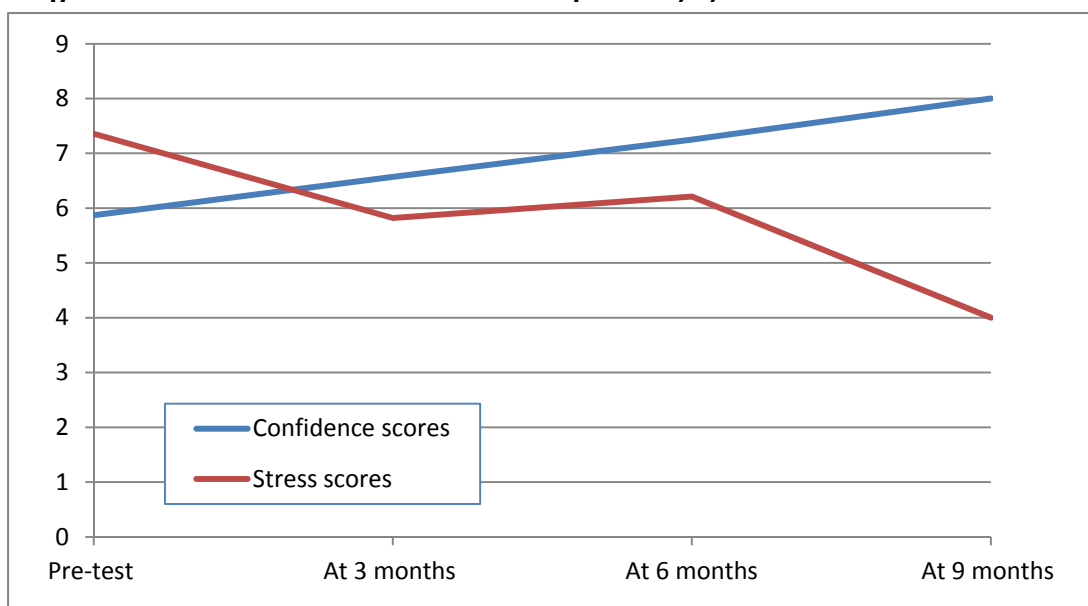
- The project resulted in improved client confidence and reduced stress (see data in Table 2 below).

<b>Table 2. Confidence and stress scores at pre-test, 3, 6 and 9 months</b>		
	<b>Confidence scores</b>	<b>Stress scores</b>
<b>Pre-test</b>	5.87	7.36
<b>At 3 months</b>	6.57	5.82
<b>At 6 months</b>	7.25	6.21
<b>At 9 months</b>	8.00	4.00

Source: AST, 2012b

These data are presented graphically in Figure 1 below.

**Figure 1. Confidence and stress scores at pre-test, 3, 6 and 9 months**



Source: AST, 2012b

Such positive outcomes are consistent with the research literature cited above. As noted, studies have shown that caregivers who receive individual and family counselling, and attend support groups, have significantly better self-reported health (Mittelman et al., 2007). For example, counselling and support interventions have been shown to reduce depression; caregivers who received counselling and support interventions exhibited fewer symptoms of

depression (Mittelman et al., 2004). Similarly, combinations of counselling and support interventions can reduce depressive symptoms (Mittelman et al., 2008).

### **3.2.2 Education Workshops and Resources**

AST offers educational workshops and resources spanning a broad range of topics in dementia and caregiving issues; a full annotated list can be found in the Appendix (Table 1). Examples include:

- *Alzheimer's 101* provides family caregivers with information on Alzheimer's disease, coping strategies and available community services for support and learning
- *The Journey Continues* workshop provides information on the middle stages of Alzheimer's disease and explores topics on communication, understanding and managing behaviors for family caregivers of individuals
- Other workshops examine different types of stress encountered by caregivers along with coping strategies; increase understanding of the progression of Alzheimer's disease and offer care strategies; and explore lifestyle changes to reduce the risk of developing Alzheimer's disease
- Webinars examine topics of caregiver stress and key aspects of LTC
- Online resources and materials on dementia, brain health and caregiving are available in different languages. An on-line course, *Alzheimer 101*, is also available.

Different workshops are offered at AST and at different locations across Toronto. AST social workers conduct workshops for family members and persons with dementia, and PECs address "issues pertaining to Alzheimer's disease and other dementias" for health care professionals and the general public (AST, 2013f).

**Program data.** The AST 2012/13 Year End Report shows that enrollment in education workshops expanded considerably between 2011/12 and 2012/13; as shown in Table 3 below, total hours rose by more than half (+55%), as did client numbers (+54%) (AST, 2013e).

<b>Table 3. Intake data, education workshops, 2011/12 and 2012/13</b>			
	<b>2011/12</b>	<b>2012/13</b>	<b>% change</b>
<b>Total hours of group education hours</b>	210	326	55%
<b>Number of clients in group education workshops and events</b>	1,107	1,700	54%

Source: AST, 2013e

**Outcomes.** Evaluations conducted in-house by AST revealed positive outcomes. Analysis of 689 responses showed that:

- Almost all participants (99%) felt workshops were a "good use of their time"

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- A majority “agreed” (37.2%) or “strongly agreed” (58.2%) they gained valuable knowledge and understanding of Alzheimer’s disease
- All agreed their overall knowledge of Alzheimer’s disease had increased
- Education workshops were described as “useful” and “exceptional.”

Results from additional evaluations of individual workshops were similarly positive. For example:

- *Alzheimer’s 101* workshop evaluations (N = 98) showed that most participants “agreed” (48%) or “strongly agreed” (42%) that the workshop provided them with “strategies in caring for a person with dementia”
- Participants in *The Journey Continues* workshop (N = 29) either “agreed” (45%) or “strongly agreed” (55%) that they had increased their understanding of how to deal with inappropriate or aggressive behaviours
- Participants in the *Alzheimer Society Services: A Place to Begin* workshop (N = 34) “agreed” (38%) and “strongly agreed” (59%) that it had increased “their understanding of services offered by other community agencies.”

Examples of participant comments include:

- *“Excellent workshop - I liked the way she involved all of us and gave us a chance to share own concerns, questions and experiences - video was good. The specific examples of how to deal with behaviours were very helpful.” (The Journey Continues workshop)*
- *“Timely - a breathe of spiritual fresh air. The workshop reminded me how much I have in my arsenal of mindful information - it really helped - thank everyone” (Mindfulness Based Stress workshop)*
- *“You were able to expand my understanding of the disease and support services.” (Alzheimer’s 101 workshop).*

### ***3.2.3 Support Groups***

According to AST, Support Groups for persons with dementia and their caregivers aim to foster mutual aid, help family members cope with stressful life events and enhance their coping abilities. They offer an environment “to meet and share with others who may be experiencing the same things,” develop a sense of belonging, form meaningful relationships and learn about coping strategies (AST, 2013g).

Support Groups vary in terms of focus and approach. A number of these groups focus on different types of dementia such as early-onset dementia, frontotemporal dementia, Lewy Body dementia, vascular dementia, and HIV related dementia. Other groups provide a safe

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forum for different types of caregivers such as the *Youth Caregiver Support Group* and the *Men's Cooking Group* targeted at younger caregivers and male caregivers respectively. Some groups are offered on a short-term basis, while others are ongoing. A full list of the Support Groups can be found in the Appendix (Table 2).

**Program data.** As shown in Table 4, AST provided 123 hours of Support Groups in 2011/12; this rose to 143 hours in 2012/13, an increase of +16% (AST, 2013e). The number of clients in the support groups rose from 368 to 503 over the same period, a 37% increase (AST, 2013e).

	<b>2011/12</b>	<b>2012/13</b>	<b>% change</b>
<b>Total hours of Support Group</b>	123	143	+16%
<b>Number of clients in Support Groups</b>	368	503	+37%

Source: AST, 2013e

**Outcomes.** While limited, evaluation results suggest that support groups were valued by participants and considered a “good use” of their time.

For example, with respect to the *Men's Cooking Group*:

- 80% of those completing evaluations (N = 5) either “agreed” or “strongly agreed” that they were “better able to recognize [their] symptoms of stress” and better able to cope with stress
- All (100%) either “agreed” or “strongly agreed” that they had a “better understanding of how to prepare a heart healthy meal” as a result of attending the group.

Written comments from *Men's Cooking Group* participants include:

- “Great experience”
- “Carry on a valuable effort”
- “Good to hear how others are coping.”

Regarding the *Ambiguous Loss Support Group*:

- All participants who completed evaluations (N = 11) either “agreed” (64%) or “strongly agreed” (36%) that they were better at recognizing their grief related to caregiving
- Most participants (82%) either “agreed” or “strongly agreed” that they were able to use Pauline Boss’ concepts to view their caregiving role

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- 10 out of 11 participants either “agreed” or “strongly agreed” that their coping ability as a caregiver had increased.

Written comments about the *Ambiguous Loss Support Group* include:

- *“Great environment, very positive experience”*
- *“Very strong facilitator, very grounded directions and attention to each attendee as individual”*
- *“The candid atmosphere - The unique balance of individual circumstances.”*

These findings are consistent with the results of a 2011 evaluation of AST support groups “for family caregivers and persons with early-stage dementia” (Hum, 2011). This evaluation considered groups for Early-Onset Dementia, Frontotemporal Dementia, Lewy Body Dementia, and Vascular Dementia. The findings showed that:

- The support groups are valued by family caregivers because they provided needed information, socialization and emotional support
- All respondents felt “fairly” (50%) or “very” (50%) prepared for the future
- All respondents agreed that it was “very helpful being with others in similar situation.”

Respondents commented that:

- *“Attending the group has a calming effect on my otherwise stressful life in trying to do my very best in the care of my folks...”*
- *“I really value this group and feel very fortunate to be part of it. It is a place where I can openly talk about dementia without having to explain everything.”*

### ***3.2.4 Creative Therapy Programs***

According to AST, Creative Therapy Programs are designed to provide opportunities for persons with dementia and their family members to “share experiences, to develop a sense of fellowship, and to relax” (AST, 2012c). These activities can improve communication between persons with dementia and their family members, improve mood and decrease isolation.

Some examples include the *Art in the Moment: Art Gallery of Ontario (AGO) tours*, *Non-impact Aerobics (Nia)* and *Dance Therapy*. The *Saturday Caregiver Retreat* is designed for caregivers to explore different forms of expressive art (e.g., poetry, painting and collage), to learn about basic relaxation and mindfulness techniques such as meditation and visualization, and to discuss and share caregiving experiences; workshops offered at the *Retreat* are hands-on and interactive.

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AST has recently launched a new program, *Music and Memory: iPod Project*, to help caregivers overcome challenges in communication and to assist people with dementia to rediscover pleasure (AST, 2013h). By bringing personalized music to people with dementia, it is thought that they can be stimulated and engaged thus diffusing agitation (AST, 2013h). While the program has not yet been evaluated (an evaluation is planned), a quote from a caregiver suggests its benefits:

- *“Mum loves the IPOD, it is making a huge difference at medical appointments... otherwise she is anxious and restless”*

**Program data.** AST provided 55.5 hours of creative therapy programs in 2011/12, and 70.5 hours in 2012/13, an increase of +27% (Table 5). The number of clients in the creative therapy programs rose from 211 in 2011/12 to 281 in 2012/13, an increase of +33%.

<b>Table 5. Intake data, creative therapy programs, 2011/12 and 2012/13</b>			
	<b>2011/12</b>	<b>2012/13</b>	<b>% change</b>
<b>Total hours of creative therapy programs</b>	55.5	70.5	+27%
<b>Number of clients in creative therapy programs</b>	211	281	+33%

Source: AST, 2013e

**Outcomes.** AST provided evaluation results for two creative therapy groups (See Appendix – Table 3). They show that:

- For the *Saturday Caregiver Retreat*, all of the participants (N = 6) rated their experience as “excellent”
  - *Retreat* participants indicated that they benefited from:
    - “Interaction with other caregivers”
    - “Knowing I’m not alone - feeling the fellowship and the support of others - the facilitators were great”
    - “Connecting with other caregivers who understand how I feel and can empathize”
    - “The tranquility of the group and the feeling of all being in the same situation and how to deal with it.”
- For the *Art in the Moment: AGO Tour*, all respondents (N = 9) rated their experience as a “4” or “5” out of 5.
  - A majority of respondents (7 out of 9) “felt more relaxed”
  - Participants commented that:
    - The tour “enabled us to become more comfortable in sharing an experience together”
    - The coffee hour afterwards is “an amazing experience where I could relate with others who suffer from dementia”.

### **3.3 Client Perspectives**

Our focus groups and interviews with clients confirmed these positive outcomes.

Clients identified a number of strengths of the CP including:

- **AST is client-centred.** Services are personalized, friendly, welcoming, non-threatening, confidential, and emphasize relationship building. Social workers are responsive and flexible to individual needs. There is minimal paperwork (no contracts), no time limits, and no formal waitlists.
- **The Counselling Program is a valuable support for caregiving.** Participants saw counselling as a “core strength.” Social workers were always available and worked with great flexibility to meet the needs of caregivers. Social workers also acted as system navigators to connect clients with different resources within and beyond AST.
- **Support groups offer essential opportunities to build skills and connect with peers.** In addition to learning new skills (e.g., coping strategies, tax tips), support groups provide opportunities to share, listen and learn which “gave me hope” and “normalize[d] what was happening.” Participants said they were able to develop friendships. Because support group membership was relatively stable, participants were able to engage in “deeper sharing.”
- **The Alzheimer Society of Toronto website is a valuable first point of contact.** Shortly after a family member was diagnosed with dementia, clients searched for support for Alzheimer’s disease and other dementias on the internet. They found AST and sought out the Counselling Program. Other clients were referred to the AST website by their physicians.
- **The Counselling Program contributes to improved mental health for caregivers.** Clients stated that using the counselling services and attending support groups improved their overall mental health. They said that knowing there is someone to call for help, and that other people are facing similar struggles, helped improved their confidence and reduced anxiety.

Clients also perceived some challenges. For example, some observed that:

- **Location is an issue.** The high costs of transportation and parking when attending programs at the Eglinton office can stand in the way of clients who need to travel, often significant distances.
- **There are not enough spaces in support groups.** Some clients said they had to wait for months to participate in a support group of their choice. During waits, they felt lost, particularly if individual counselling was not what they desired. Aside from expanding support groups, waitlisted clients could be connected to volunteers to get support and normalize their feelings.



- **Other health care providers are not aware of AST.** Other health professionals and organizations did not seem to know or did not tell clients about AST. More partnerships with geriatric teams and other providers could increase awareness and facilitate quicker connections with AST.

### **3.4 Key Informant Perspectives**

#### **3.4.1 Senior Managers**

Our in-depth interviews added valuable insights into the current design, operation and outcomes of the CP, as well as its future potential.

Among its perceived strengths:

- **AST is unique.** AST provides a wide range of services and programs specifically for caregivers and person with ADOD. Clients are served at any point in the disease progression. Dementia care is the “core business” and AST is the “go-to” organization for specialized expertise
- **AST fills a crucial gap for people.** As the population ages, and more older persons and caregivers grapple with ADOD, AST provides vital counselling, peer support, education and skills development. AST is offering more support groups, social events and creative therapy sessions for persons with dementia. Creating day programs and respite care may further expand access (although AST has no desire to duplicate services offered by other providers)
- **AST plays a vital system role.** In addition to supporting caregivers and persons with ADO directly, it enhances system capacity by providing essential education to care professionals, and building partnerships with other providers. Programs like *First Link* and the collaborative project with the TC CCAC facilitate quicker referrals and access to needed supports.

Among the challenges:

- **Lack of awareness among people and providers.** In spite of best efforts, too few people and providers seem to know about AST and its CP. New marketing/communication approaches using web-based technologies and social media could be used to engage the public and raise awareness about AST and the value its programs offer
- **Limited market reach.** Key informants observed that AST currently reaches only a small proportion of caregivers and persons with ADOD in Toronto. More could be done to “get out there” and connect with people and providers that could benefit from AST’s vital expertise

- **Funding is not secure.** Current funding comes from a mix of sources including government, corporations and individuals. While allowing AST considerable independence, this results in a cautious approach to growth opportunities
- **There are disconnects between the national Alzheimer Society, provincial offices and local chapters.** While there is extensive collegial interaction between local, provincial and national staff at the Toronto headquarters, there is no clearly elaborated framework or pathways for collaboration; local chapters all have different websites, services, programs and approaches. Given that the Alzheimer Society has national reach, there is considerable potential for it to lead local, provincial and national efforts to build evidence, develop benchmarks, and identify and “spread” best practices around ADOD.

### **3.4.2 Social Workers and Public Education Coordinators (PECs)**

Social workers and PECs elaborated and reinforced key themes identified by clients and managers. For example, they observed that:

- **AST is special.** Ongoing support and services for caregivers and persons with ADOD throughout the progression of the disease are rarely offered elsewhere in the community. The education and support groups are innovative and responsive to clients’ diverse needs. AST’s team of passionate and dedicated people goes the extra mile to meet client needs
- **AST offers essential education and support to the public and professionals.** AST fills crucial gaps in dementia care in Toronto. For example, support groups for specific dementias are not commonly available elsewhere. AST also connects clients to other needed providers and services (e.g., day programs, respite care). This role will become even more essential as the population ages and as more older persons and caregivers cope with ADOD.
- **AST is well positioned to lead dementia care into the future.** Social workers and PECs identified a number of areas of particular opportunity:
  - **Education.** There is a vision for AST to become an Institute or College for dementia education so that healthcare professionals can be better trained and educated to serve their communities
  - **Service.** AST should consider expanding into direct service provision including respite care, day programs and social programming at all stages through the disease’s progression
  - **Technology.** AST is currently offering e-learning and webinars, and implementing an iPod Project to engage and reach out to caregivers and persons with dementia. There are many additional opportunities to use innovative technologies and strengthen AST’s online presence to be more user-friendly.

- **AST and its clients gain from expanded collaborations with other agencies.** Initiatives such as *First Link* demonstrate the benefits of building collaboration with other providers to smooth referrals and lever capacity. Collaborations can help to reach out to underserved communities. AST has already developed valuable partnerships with community organizations such as SPRINT (Senior Peoples’ Resources in North Toronto), Etobicoke Services for Seniors, St. Clair West Services for Seniors, Providence Healthcare, Scarborough Centre for Healthy Communities, Casey House, and The 519 Church Street Community Centre. New collaborations could include hospitals (e.g., CAMH) and organizations (e.g., Heart and Stroke) that focus on brain health and aging.

Social workers and PECs identified some challenges:

- **Geographic accessibility is an issue.** Although AST provides excellent services in multiple locations, some groups and communities are still underserved. For example, it was noted that caregivers living in Scarborough and Etobicoke are less likely to take advantage of the CP because of the location of the main office.
- **Language and cultural barriers persist.** Current offerings tend to be for English-speaking people, with newer and emerging language and cultural communities receiving less attention. While AST does offer services in Mandarin, Cantonese, Spanish and Greek languages, gaps remain. Since no single organisation can span all needed languages and cultural contexts, AST could benefit from partnerships with agencies in cultural communities. Both language and culture need to be addressed since different communities may view dementia and caregiver roles in different ways, and accept different approaches to supporting persons with ADOD.
- **Current staffing levels are insufficient for greater outreach.** While there was a strong sense that AST could be doing more to connect with local communities, human resources limit significant expansion to satellite locations, particularly since additional staff time would be required to make arrangements and travel to these locations.
- **There are not enough offerings for individuals at later stages of the disease progression.** Current programming tends to focus on persons in the early stages of dementia; persons with dementia at later stages need more attention.

### **3.5 Think Tank**

Our half-day Think Tank used Twitter as an interactive platform for sharing, discussing and responding to ideas raised in real time. Participants were asked “how best to sustain, scale-up and spread AST programs and services.” A number of consistent themes emerged.

- **Target caregivers and persons with ADOD early in the disease progression.** Early intervention, as soon as possible after diagnosis, gives greater scope to provide education, plan care and link to needed services before crisis occurs. AST should build on the success of its *First Link* program.

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- **Coordinate, don't duplicate.** Advanced planning workshops, early onset dementia support groups and exercise programs are examples of essential resources which aren't available elsewhere. Other services like adult day programs and respite are already provided by other agencies.
- **Strengthen outreach to increase awareness and access.** AST is currently operating more than ten satellite clinics across Toronto and there are also external education sessions for caregivers, persons with dementia and the general public. Nevertheless, participants emphasized that there is a need for greater outreach to underserved populations. Opportunities include greater use of community spaces including supportive housing, nursing homes, day programs and retirement homes.
- **Expand use of e-technologies.** While persons with ADOD may not use e-technologies, many caregivers make extensive use of Google searches, web sites, and social media. Development of the *Senior Health Knowledge Network* and creation of YouTube videos could make information more accessible and increase public awareness. Similarly, referrals might be improved by expanding *First Link* to include EMR (emergency paramedics), family health teams and social workers. Innovations such as "virtual rounds" where agencies use electronic platforms jointly to review cases and build care plans could facilitate better care for individuals and stronger inter-agency linkages.
- **Establish new partnerships and build on existing partnerships.** In addition to strengthening existing partnerships with long-term agreements, consider establishing new partnerships with pharmaceutical companies, pharmacists and memory clinics.

When asked to identify the essential elements of a business case for the CP, participants emphasized the following:

- **AST is a valuable investment.** AST programs and services provide essential client-centred care. AST provides "one-stop shopping" for caregivers and persons with ADOD.
- **Lever partnerships, volunteers, and technology-enabled learning.** Collaborations like *First Link* build system capacity. More could be done by training volunteers to engage in peer counselling and home visits and using webinars and social networking to open new avenues for education and support.
- **Develop a registry for persons with dementia and their caregivers.** It was noted that Cancer Care Ontario operates a cancer registry which collects information from multiple sources including patient consultation and treatment records; the registry is a valuable resource for policy-makers and researchers aiming to improve cancer care. A similar registry could be established for ADOD to document its growing importance and alternative approaches to care. The creation of a registry would also serve to validate the experiences of caregivers and persons with ADOD.

## 4.0 Recommendations

Early in this report, we introduced “Mary,” a daughter caring for her aging mother with Alzheimer’s disease. Mary felt guilty and alone, did not know where to turn, and worried that she would not be able to continue to care. Mary connected with AST and things changed for the better.

### Recalling Mary

- After Mary found out about the Alzheimer Society on the internet, she began receiving one-on-one in-person counselling
- Following the advice of her social worker, she joined the *Coffee Hour for Caregivers* which met informally over a four week period
- Mary’s mother also began attending the *Early Stage Dementia Support Group*, a program for people in the early stages of dementia
- Mary took part in the on-line education session *Alzheimer 101*
- Mary told us that support from other group members was the best part of her experience. She was grateful for the insights into the disease that social workers provided
- Mary has made friends with other group members and is allowed to laugh. She has learned that her feelings are “normal.” Mary now realizes that she is not alone and that she can get the help she needs to continue to care for her mother.

Our review of the research and policy literatures emphasizes that Mary is not alone -- the ranks of caregivers with similar experiences will grow as the population ages.

This could auger bad news for caregivers and persons with ADOD, if they don’t have access to essential education, counselling and support. But it also promises bad news for the health care system, which, without such supports in place to sustain caregivers and cared-for older persons where they live, can expect to see increasing numbers of “defaults” to costly and often inappropriate hospital and institutional care, driving up system costs, and threatening sustainability.

In Ontario, and beyond, there is a clear shift in thinking (if not yet commensurate action) toward community-based health promotion, primary health care, and management of chronic needs. There is also increasing awareness not just of the crucial role of informal caregivers in supporting high needs older persons, and avoiding costly health care, but of the logic of providing caregivers with the resources needed to maintain caregiving resilience and capacity. Moreover, there is a growing push toward greater collaboration between providers at the local level (e.g., Health Links) to build linkages, lever available resources and smooth transitions between “silos” particularly for persons with high complex needs and caregivers requiring multiple services from multiple providers.

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The Counselling Program of the Alzheimer Society of Toronto is strongly aligned with these developments and strategic directions. It is also aligned with a growing and persuasive body of research evidence that access to individual and family counselling, psycho-educational programmes, specialized skills training, multicomponent programmes, psychotherapy/cognitive behavioural therapy, and exercise programs can reduce caregiver stress, increase confidence, and increase caregiver capacity and resilience. AST's innovative *First Link* program has been recognized as a "best practice" to be scaled-up and spread across Ontario.

Moreover, the CP received strong and consistent support from clients, staff, managers and external stakeholders who judged it to provide high value to people, providers and the health system as a whole.

For example, CP data suggested that one-on-one counselling did reduce caregiver stress while increasing confidence. Education workshops were judged by clients to be excellent and a good use of their time. Participants in educational workshops said they were instrumental in increasing knowledge of ADOD, developing coping strategies, learning how to manage challenging behaviours, and increasing their understanding of related services in the community. Support group clients said they developed a sense of belonging and community, fostered meaningful relationships, and promoted sharing of experiences. Creative therapy groups were seen by clients to provide opportunities to engage in meaningful activities which improved mood and decreased isolation. Caregivers participating in the *Art in the Moment: AGO tours* and *Saturday Caregiver Retreat* described the experience as "amazing" because of peer support and a sense of belonging. Clients viewed the availability and flexibility of social workers, and the personalized client-centred approach of the CP, as core strengths.

Senior managers, social workers and PECs judged that the CP offers high quality services to caregivers and persons with ADOD. They emphasized that the CP fills a knowledge and practice gap not just among clients, but among provider organizations and professionals. They identified opportunities in education, service and technology that can bolster AST's leadership in the field.

Of course, the job is never done. Given rapidly growing need, the big question for many respondents was how to scale-up, spread and sustain the success of the CP.

Many constructive responses had to do with adjustments to program content and design (e.g., additional offerings for caregivers and persons with ADOD early in the disease progression; additional social programming); others pointed to strategic change. Our recommendations reflect both perspectives.

**Recommendation 4.1. Build on the success of the CP.** The CP is strongly aligned with key research and policy directions; from multiple perspectives, it has achieved considerable success. Given the rising number of caregivers and persons with ADOD, and the growing challenges to health system sustainability, the CP should continue to expand.



**Recommendation 4.2. Spread *First Link*.** *First Link* has been identified as an exemplar of what can and should be done across Ontario to respond to the growing needs of caregivers and persons with ADOD. AST can use this political momentum to engage a wider range of providers and organizations, and to communicate the value of the CP to planners, policy-makers and funders.

**Recommendation 4.3. Engage in Health Links.** AST should be “at the table” as Health Links gain traction. Through Health Links, AST can increase awareness of the value of its CP at individual and system levels. It can assist other professionals, providers and decision-makers to understand the needs and care trajectories of caregivers and persons with ADOD, who are already, or who may become, without appropriate community-based supports, high health care utilizers.

**Recommendation 4.4. Create new partnerships and collaborations.** Current collaborations with the TC CCAC and community agencies demonstrate the ability to lever resources and reach out to people and communities impacted by ADOD. In addition to family health teams, community health centres, and community support agencies, future collaborations might include community-based providers who have regular “first-line” contact with caregivers and persons with ADOD including pharmacies and memory clinics. More partnerships with providers in diverse communities could ease barriers to access associated with language and culture.

**Recommendation 4.5. Reach out to underserved communities.** Many caregivers and persons with ADOD who could potentially benefit from the CP, may not be able to access it because of mobility restrictions, or because of language and cultural differences. While AST does not have the resources to offer and sustain a full range of services and programs in diverse communities on its own, it could expand partnerships with other agencies to mount workshops, support groups and creative therapy groups “in community spaces” where older persons of diverse cultures congregate, including supportive housing, nursing homes, home care facilities and retirement homes.

**Recommendation 4.6. Make the most of e-technologies and e-learning.** More and more caregivers and persons with ADOD are web-savvy and use social media to educate themselves and find services. AST already provides a selection of web-based resources including webinars and on-line courses. User-friendly web-based technologies could also be used to link providers, facilitate virtual inter-disciplinary teams, reduce travel time, encourage knowledge sharing, and smooth transitions. YouTube videos in different languages could increase awareness in diverse communities and link people to the CP.

**Recommendation 4.7. Maximize the potential of the Alzheimer Society national infrastructure.** AST is one of a few community-based agencies with access to highly developed provincial and national infrastructures. Such infrastructures offer considerable potential to identify innovations and best practices in care for caregivers and persons with ADOD locally,

provincially and nationally. This is of increasing relevance as different jurisdictions grapple with new challenges including those connected to an apparent rise in challenging behaviours in the community and in residential LTC. While employing a full-scale research staff is likely not an option for AST, it could work more closely with its provincial, national and international counterparts to build the evidence base.

**Recommendation 4.8. Advocate for an Alzheimer’s strategy “from the ground up.”** Ontario does not currently have a provincial Alzheimer’s strategy; Canada has never had one. From a pessimistic perspective, this policy vacuum is alarming given an aging population and rising numbers of persons with ADOD. From a more optimistic perspective, this offers considerable opportunity to use AST resources and expertise to help build a strategy “from the ground up.” Such a strategy could be assisted by the development of an ADOD registry similar to that used by Cancer Care Ontario, which, in addition to documenting numbers and characteristics of people, could document promising approaches to care.

**Recommendation 4.9. Systematically document and disseminate the “facts” and the “faces” of the CP.** It is a truism of political advocacy that while administrators and bureaucrats prefer science, policy-makers (and providers) first want to know about the impact on the lives of people. As the CP expands and evolves it is crucial to collect and analyze the numbers and characteristics of the people it serves, and outcomes at individual, organization and system levels. Not only does this encourage continuous learning and innovation, it equips AST with a crucial resource to demonstrate its value to external stakeholders and strengthen its “business case.” Standard intake protocol and client records, as well as ongoing assessment, are essential.



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## Appendix

<b>Table 1. List of the education workshops, goals and target audiences (an asterisk denotes workshops for which data were available)</b>		
<b>Workshop Name</b>	<b>Goals</b>	<b>Target Audience</b>
*Alzheimer Society Services: A Place to Begin	<ul style="list-style-type: none"> <li>To provide general information about the programs and services offered at the Alzheimer Society of Toronto</li> </ul>	General public
*Alzheimer's 101	<ul style="list-style-type: none"> <li>To provide information on Alzheimer's Disease, coping strategies and the available community services</li> </ul>	Family caregivers
Alzheimer 101- On-line module	To provide information on Alzheimer's Disease, coping strategies and the available community services	Persons with dementia and Family caregivers
*Caregiver Stress	<ul style="list-style-type: none"> <li>To examine the different types of stress caregivers may experience and develop coping strategies to deal with the stress</li> </ul>	Family Caregivers
*Early Stage Workshop	<ul style="list-style-type: none"> <li>To increase understanding of the progression of Alzheimer's disease</li> <li>To offer strategies in caring for a person with dementia</li> </ul>	People in the early stages of Alzheimer's disease and their family members
*Heads up for Healthier Brains	<ul style="list-style-type: none"> <li>To identify and understand the risk factors associated with Alzheimer's disease</li> <li>To explore the lifestyle changes/improvements to reduce the risk of developing Alzheimer's disease</li> </ul>	The general public
*The Journey Continues: Communication and Behaviour Strategies	<ul style="list-style-type: none"> <li>To address how dementia impacts communication and possess strategies</li> <li>To offer a tool to investigate why responsive behaviours occur and recognize how to design an appropriate intervention</li> </ul>	Family caregivers of individuals in the middle stages of Alzheimer's disease
*Long-Distance Caregiving	<ul style="list-style-type: none"> <li>To explore the unique challenges and issues when caring for someone from a distance</li> <li>To connect to agencies in other cities for support</li> </ul>	Family caregivers who live out of town

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*Meaningful Activities	<ul style="list-style-type: none"> <li>To increase knowledge and understanding of appropriate activities to do with a family member with dementia</li> </ul>	Family caregivers
*Mindfulness Based Stress	<ul style="list-style-type: none"> <li>To better recognize symptoms of stress</li> </ul>	Family caregivers
*Other dementias	<ul style="list-style-type: none"> <li>To increase understanding of vascular dementia, lewy-body dementia and frontotemporal dementia</li> </ul>	Family caregivers
*Overview of Alzheimer's disease	<ul style="list-style-type: none"> <li>To inform about Alzheimer's disease and how it affects individual's abilities</li> <li>To increase understanding of risk factors associated with Alzheimer disease</li> </ul>	General public
Palliative Care Workshops for families	<ul style="list-style-type: none"> <li>Offered in collaboration with Hospice Association of Ontario (HAO), family caregivers will gain knowledge and skills in caring for people with dementia at the end of life</li> </ul>	Family caregivers
*Reducing Income Tax with the Disability Tax Credit and Medical Expense Tax Credit	<ul style="list-style-type: none"> <li>To learn from a representative of the Canada Revenue Agency about the disability tax credit and medical expense tax credit for tax relief</li> </ul>	General public
Living Well with Dementia	<ul style="list-style-type: none"> <li>To educate about the progression of Alzheimer's disease and to explore coping strategies</li> </ul>	Persons in the early stages of Alzheimer's disease and their family members
Advance care planning	<ul style="list-style-type: none"> <li>To explore advance care planning, Power of Attorney, role of a substitute decision-maker, and consent</li> </ul>	People with Alzheimer's disease and other dementias and their family caregivers
Bringing Choices to Late-Stage Care	<ul style="list-style-type: none"> <li>To recognize the symptoms of the late and end stages of Alzheimer's disease</li> <li>To provide knowledge of the types of ethical dilemmas that may arise in end of life care planning</li> </ul>	Family caregivers
Care Essentials (part of <i>First Link</i> series)	<ul style="list-style-type: none"> <li>To provide knowledge of Alzheimer Disease, and strategies to effectively communicate, manage behavioural changes, and support the person with dementia with meaningful activities</li> </ul>	Family caregivers of people in the middle stage of dementia
Care in the Later Stages (part of <i>First Link</i> series)	<ul style="list-style-type: none"> <li>To discuss changes in the late and end of life stages</li> </ul>	Family caregivers of those in the late stage of dementia



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	<ul style="list-style-type: none"> <li>• To explore care strategies for the later stages</li> <li>• To learn and apply new self-care strategies</li> </ul>	
First Steps (part of <i>First Link</i> series)	<ul style="list-style-type: none"> <li>• To educate about how dementia impacts the brain and how to keep their brain healthy</li> </ul>	People in the early stage of dementia and their family caregivers
Next Steps (part of <i>First Link</i> series)	<ul style="list-style-type: none"> <li>• To identify ways that they have been adapting to dementia and evaluated the effectiveness of those adaptations.</li> <li>• To develop a plan for supporting the person in their lives with dementia to manage their finances</li> </ul>	Family caregivers
Day-to-Day Life in Long-term Care	<ul style="list-style-type: none"> <li>• To assist caregivers prepare and adjust to their family member entering a long-term care facility</li> </ul>	Family caregivers
Montessori Training for Families	<ul style="list-style-type: none"> <li>• To examine the Montessori method of creating and presenting activities</li> </ul>	Family caregivers
Activities to do with your family member	<ul style="list-style-type: none"> <li>• This workshop will help caregivers find effective activities for their family member. The goal is to give practical ideas on how family members can spend quality time together by identifying and drawing upon the person's remaining strengths</li> </ul>	Family caregiver
Moving to Long-Term Care (set of three workshops)	<ul style="list-style-type: none"> <li>• To review and discuss the dilemma for making the decision to LTC</li> <li>• To discuss and assess caregiving options in the home, LTC and retirement home</li> </ul>	Family caregivers
WEBINAR – Caregiver Stress	<ul style="list-style-type: none"> <li>• To learn about the signs of caregiver stress, coping strategies, and benefits of counselling and support</li> </ul>	Family caregivers
WEBINAR – LTC: Adjustment and Day-to-day Life	<ul style="list-style-type: none"> <li>• To learn about strategies that can help persons with dementia adjust into long-term care, caregiver coping strategies, advocacy and communicating with staff</li> </ul>	Family caregivers
WEBINAR – LTC: Preparing for the Move	<ul style="list-style-type: none"> <li>• To learn how to prepare for a move after making an application to long-term care, suggestions for moving day and caregiver coping strategies</li> </ul>	Family caregivers
WEBINAR – Overview of Alzheimer's Disease	<ul style="list-style-type: none"> <li>• To learn about Alzheimer's disease and other dementias, the impact of changes to the brain, the progression of Alzheimer's disease, strategies to reduce risk factors</li> </ul>	General public

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	and how the Alzheimer Society of Toronto can help	
Webinar – Brain Health	<ul style="list-style-type: none"> <li>To understand the risk factors of Alzheimer's disease and improving and maintaining the health of the brain</li> </ul>	General public

<b>Table 2. List of support groups, goals and target audiences (an asterisk denotes workshops for which data were available)</b>		
<b>Support Groups</b>	<b>Goals</b>	<b>Target Audience</b>
*Living with Ambiguous Loss	<ul style="list-style-type: none"> <li>To learn to cope with ambiguous loss-support group</li> </ul>	Family caregivers
*Men's Cooking Group	<ul style="list-style-type: none"> <li>To develop support group for men</li> </ul>	Male partners of someone with dementia
Early Stage Dementia Support Group	<ul style="list-style-type: none"> <li>To improve the quality of live through learning and sharing coping strategies</li> </ul>	People with early stage dementia
Coffee Hour For Caregivers	<ul style="list-style-type: none"> <li>To lower stress and anxiety</li> </ul>	Family caregivers for persons with early stage Alzheimer's Disease
Early Onset Family Support Group	<ul style="list-style-type: none"> <li>To provide therapeutic support and coping strategies for caregivers of someone with early onset dementia</li> </ul>	Family members of someone with early onset dementia
Early Onset (under 65) Support Group for People with Dementia	<ul style="list-style-type: none"> <li>To provide support for people with early onset dementia</li> </ul>	People with early onset dementia (not currently offered)
Frontotemporal Dementia Family Support Group	<ul style="list-style-type: none"> <li>To provide therapeutic support</li> </ul>	Family members of those diagnosed with Frontotemporal Dementia
Lewy Body Dementia Family Support Group	<ul style="list-style-type: none"> <li>To provide therapeutic support</li> </ul>	Family members of those diagnosed with Lewy Body Dementia
Vascular Dementia Family Support Group	<ul style="list-style-type: none"> <li>To provide therapeutic support</li> </ul>	Family members of those diagnosed with Vascular Dementia

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Youth Caregiver Support Group	<ul style="list-style-type: none"> <li>To provide therapeutic support and coping strategies for caregivers</li> </ul>	Teens 13 - 18 caring for someone diagnosed with dementia
HIV Related Dementia Support Group	<ul style="list-style-type: none"> <li>To support caregivers of persons with dementia and HIV</li> </ul>	Caregivers of persons with HIV related dementia

<b>Table 3. Creative therapy programs and their goals and target audience (an asterisk denotes workshops for which data were available)</b>		
<b>Creative therapy programs</b>	<b>Goals</b>	<b>Target Audience</b>
*Art in the Moment: AGO Tour	<ul style="list-style-type: none"> <li>To provide opportunities to participate in a meaningful activity with persons with dementia and their caregivers</li> </ul>	Persons with early stages of dementia and their family caregivers
*Creative Therapy Forum	<ul style="list-style-type: none"> <li>To explore different creative therapies such as Nia, horticulture, and Tragedy and Comedy</li> </ul>	Family member of people living with Alzheimer's disease and other dementias (not currently offered)
*Saturday Caregiver Retreat	<ul style="list-style-type: none"> <li>To learn from the experience and insights of others on coping strategies</li> <li>To discuss and practice self-care strategies</li> </ul>	Family member of people living with Alzheimer's disease or other dementias
Dance Therapy	<ul style="list-style-type: none"> <li>To explore movement in a fun, engaging and meaningful way</li> </ul>	People with dementia and their family caregivers
Nia: Non-impact Aerobics	<ul style="list-style-type: none"> <li>To engage people with dementia and their family caregivers in a dance workout</li> <li>To reduce caregiver stress</li> </ul>	People in the early stages of dementia and their family caregivers
Rhythm and Relaxation	<ul style="list-style-type: none"> <li>To provide opportunities for relaxation and fun by drumming</li> <li>To reduce caregiver stress</li> </ul>	People in the early stages of dementia and their family caregivers
Dine and Dance in Afternoon	<ul style="list-style-type: none"> <li>Yearly dance for family caregivers and persons with dementia</li> </ul>	Family caregivers and persons with dementia
Watercolour Painting: Building new skills together	<ul style="list-style-type: none"> <li>A four session group for family caregivers and people in early stages of dementia to learn about watercolour painting</li> </ul>	Family caregivers and people in early stages of dementia (Offered as of April 2013)