



# **Alzheimer Society of Toronto – TC-CCAC Inter-professional Collaboration Project**

---

**Year-End Report  
December 21, 2012**



## **ACKNOWLEDGEMENT**

Project coordination is provided by Kelly Clarke, Liana Sikharulidze, Willemien Stanger, Sandra lafrate (TC-CCAC Client Services Managers) and Gayle Seddon (ICT team Manager). Performance indicators tracking, other data collection, management and compilation is performed by Peter Marczyk, MSW intern at AST. The author would also like to thank Anne Stephens for her invaluable input.

## Table of Contents

Table of Contents	3
1. Background	4
2. Project Objectives	4
3. Project Leadership	4
4. Project Partners and Framework	4
4.1. Project Partners	4
4.1.1. Alzheimer Society of Toronto	4
4.1.2. Toronto Central Community Care Access Centre (TC-CCAC)	5
4.2. Project Framework	5
5. Year Findings	7
5.1. Performance Indicators	7
5.1.1. Performance Indicators listed on the Project Charter	7
5.1.2. Other statistics	10
5.2. Education Sessions for Family Caregivers and CCAC Coordinators	11
5.2.1. CCAC coordinators sessions	11
5.2.1.1. Mid year findings	11
5.2.1.2. July-Dec findings	12
5.2.2. Caregivers sessions	13
5.3. Positive Impacts of the Inter-professional Partnership on Family Caregivers	14
5.3.1. Who made referrals to AST?	14
5.3.2. Contacts by Relationship and Service Types	14
5.3.3. What are being Discussed at the Counselling Sessions?	15
5.3.4. AST/CCAC Collaboration was Effective in Ameliorating Caregiver Stress	18
5.4. Feedback from staff	19
6. Success Stories	24
7. Recommendations and Conclusions	26
APPENDIX A <i>First-Link</i> Referral Form	28
APPENDIX B1 Pre-Session Participant Survey	29
APPENDIX B2 Post-Session Participant Survey	30
APPENDIX B3 Participant Session Feedback	31
APPENDIX C Legends for topics discussed between AST counsellors & caregivers	32

## **Section 1 Background**

The Alzheimer Society of Toronto (AST) proposed an inter-professional partnership with the Toronto Central CCAC, whereby AST counsellors would work in close collaboration with the CCAC, and particularly with the care coordinators from the Senior Enhanced Care Program (SEC) to expand the depth and range of services available to persons with dementia, and their family caregivers within TC-LHIN. Coincidentally, the partnership will improve access to available AST services to CCAC clients (and vice versa). In turn, clients can become more aware of different services that may help them throughout their caregiving journey.

\*\*As a result of the positive reception of the project by the SEC Coordinators, the collaboration was expanded to involve care coordinators from the Integrated Care Team (ICT) during the second half of the project.

## **Section 2 Project Objectives**

The partnership will improve services to CCAC clients and lead to a more integrated, cost-effective, family-focused system of care to reduce caregiver stress, while improving caregiver resiliency in navigating the long and difficult role of caring for a loved one with dementia at home.

The project will also develop and enhance the knowledge and skills of the SEC and ICT coordinators in caring for persons with dementia. While the degree of case management and involvement with these clients may not be reduced, coordinators' access to AST counsellors and the knowledge transfer that takes place will increase their capacity and improve their ability to work with the needs of this client population. Embedding AST counsellors with the SEC/ICT teams will improve communication and allow for a more seamless, quick response in crisis situations.

The mutual goal is to improve quality of care, and to prevent or mitigate family crises that can lead to inappropriate visits to ER, overlong stays in ALC and premature placement in long term care. By developing integrated care teams, the intention is to enhance value, improve outcomes and build greater system capacity.

## **Section 3 Project Leadership**

A core group was formed to develop the framework, and oversee the implementation and evaluation of the inter-professional project.

- Cathy Barrick, Chief Executive Officer, Alzheimer Society of Toronto (AST)
- Marija Padjen, Chief Program Officer, Alzheimer Society of Toronto (AST)
- Ann M. Semotiuk, Director of Client Services (Community Programs), Toronto Central Community Care Access Centre (TC-CCAC)
- Mary Chiu, External Evaluator of the project; Research Coordinator, Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital

## **Section 4 Project Partners and Framework**

### **4.1 Project Partners**

#### **4.1.1 Alzheimer's Society of Toronto (AST)**

The role of the Alzheimer Society of Toronto is 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. Services provided by AST to people with dementia and their caregivers include (but are not limited to): One-on-one counselling, support groups, psycho-education sessions, and a comprehensive Resource Centre. The AST counsellors( 5 social workers) and education staff( 4 education staff) also play a role in expanding the dementia knowledge base of SEC/ICT coordinators, who may then better support their clients. **The partnership with CCAC will broaden AST's education and outreach effort in the community.**

#### 4.1.2 Toronto Central Community Care Access Centre (TC-CCAC)

The TC-CCAC is a logical partner for this project as CCAC plays a unique role in system integration and delivery by providing case management, and a range of home and community-based services to support people to live in their homes and communities for as long as possible. Having adopted the *Population Based Model*, CCAC acknowledges that seniors with complex needs in the community have high clinical and other service requirements. Senior Enhanced Care (SEC) Coordinators, working together on teams, address the needs of frail seniors with complex medical, physical, cognitive and social conditions that may put them at risk for hospitalization or premature institutionalization. They provide support to caregivers in their role with an understanding of the importance of preventing caregiver burnout. In 2011, the Integrated Complex Care Program (ICCP) strategy was implemented by TC-CCAC to drive the highest possible care integration for populations who need it most. The ICCP strategy became the foundation that led to the development of the Integrated Care Teams (ICT), whose objective is to build integrated care teams at the point of care for the most medically fragile, social and functionally impaired and to work hand in hand with primary care teams.

The AST/CCAC inter-professional project enables SEC and ICT coordinators to identify and link persons with dementia (even without formal diagnosis) and their family caregivers who may benefit from aforementioned services provided by AST. Coordinators also participate in sessions for case consultation and professional development provided by AST.

#### 4.2 Project Framework

In February 2010, the *Canadian Inter-professional Health Collaborative* published a report titled “A National Inter-professional Competency Framework”. The author described **inter-professional collaboration** as:

*“the process of developing effective inter-professional working relationships with practitioners, patients/clients/families and communities to enable optimal health outcomes. Elements of collaboration include respect, trust, shared decision making, and partnerships.”<sup>1</sup>*

It is believed that inter-professional education and collaborative client-centred practice are keys to building effective health care teams and improving the experience and outcomes of patients. The “Competency Framework” proposed by CIHC has six domains: 1) inter-professional communication, 2) client-centred care, 3) role clarification, 4) team functioning, 5) collaborative leadership, and 6) inter-professional conflict resolution.

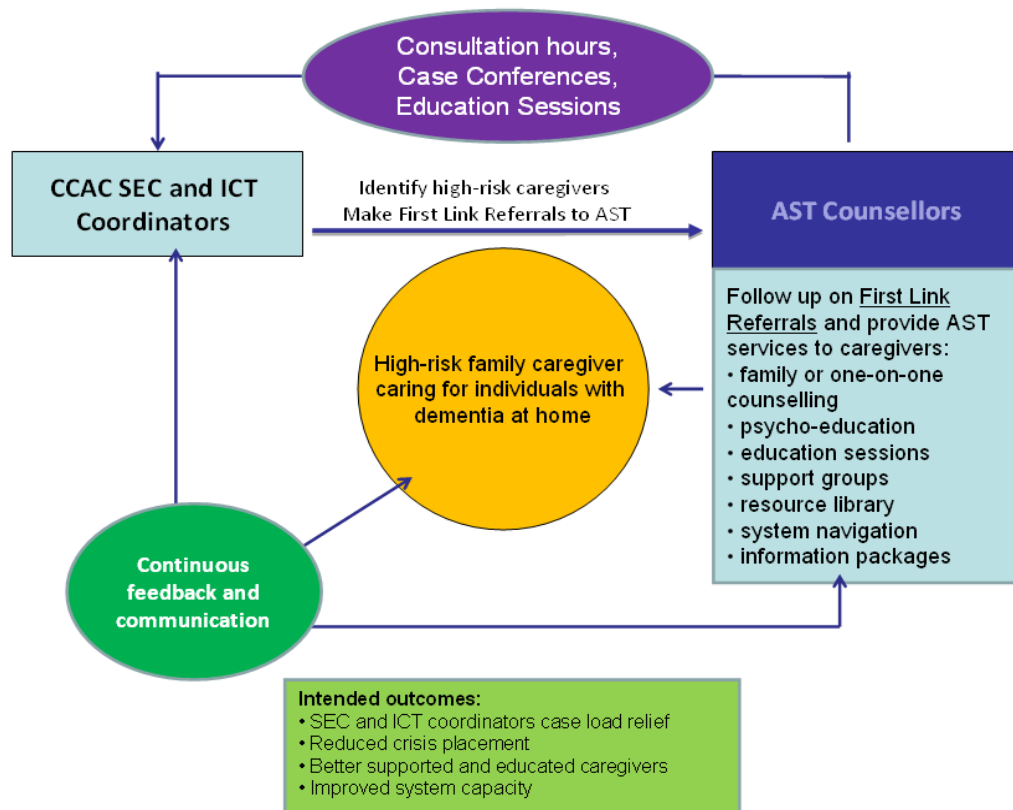
Aligning with the CIHC “Competency Framework”, the current project is built upon a client-centred model with the caregivers in the centre, and SEC/ICT coordinators and AST counsellors being the facilitating agents in system navigation and access of appropriate services.

Figure 4.1 shows a framework of the AST/TC-CCAC inter-professional partnership. CCAC SEC/ICT coordinators are instrumental in identifying and referring caregivers or families who may benefit from AST services. They complete an AST *First-Link Referral Form* (Appendix A). AST counsellors contact the referred caregivers/families and assess their dementia-related needs. Services that may be provided to caregivers include (and are not limited to): family or one-on-one counselling, psycho-education and education sessions, support groups, resource library, and system navigation (referring caregivers to other community resources). AST education specialists also provide educational support to SEC/ICT coordinators, through education sessions, consultation hours and weekly case conferences.

---

<sup>1</sup> *Canadian Inter-professional Health Collaborative* (Feb 2010), “A National Inter-professional Competency Framework.” [http://www.cihc.ca/files/CIHC\\_IPCompetencies\\_Feb1210.pdf](http://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf), accessed on Dec 10, 2012

Figure 4.1 Project framework



**Section 5**      **Year Findings**

**5.1 Performance Indicators**

**5.1.1 Performance Indicators listed on the Project Charter**

Performance indicators as listed in the Project Charter are tracked and monitored by AST and CCAC. Data available up to December 15, 2012 (unless otherwise stated) are presented in tables below.



**\*All targets listed in the 2011/12 Project Charter have been successfully met or surpassed\***

a. New Referrals to AST

*Objective:* To Increase access to services for caregivers of persons with dementia.

*Performance indicator:* Number of new referrals to AST by CCAC

*Comments:* CCAC is continuously exceeding the target in this indicator. A total of **227** caregivers (monthly average of 19 new referrals) now have better access to relevant services provided by AST. The increased number of referrals may be attributed to 1) the closer working relationship fostered between AST and CCAC, and 2) the easy-to-use *First-Link* referral forms.

Baseline in Year 2011	Target	Total New Clients by Month	
		Month	Number of New Referrals
Total of 23 referrals from CCAC	SEC/ICT Coordinators to refer 200 new clients to AST for counselling services	January	12
		February	22
		March	27
		April	25
		May	19
		June	15
		July	25
		August	17
		September	16
		October	20
		November	16
		December (1 <sup>st</sup> to 10 <sup>th</sup> )	13
		<b>Total</b>	<b>227</b>

b. Counselling hours

*Objective:* To improve caregiver health and well-being, and their capacity to care for the person with dementia at home as the disease progresses

*Performance indicator:* Number of counselling hours provided by AST counsellors

*Comments:* 1) Different caregiver needs were discussed during AST counselling sessions, and these needs are listed in Figure 5.3. 2) The reduction in counselling hours in April is due to personnel changes at AST. 3) Total hours reported here includes data projection up to December 15, 2012, and the targeted 4,800 hours of counselling for the entire GTA and 1,000 hours target for the TC-LHIN are expected to be surpassed. This would be **an increase of more than 1,000 counselling hours** from last year's baseline of 3,800 hours provided by AST counsellors to caregivers in the entire GTA.

Counselling hours (continued)

Baseline in Year 2011	Target	Total Counselling Hours by Month		
		Month	# of Counselling hrs for caregivers within TC-LHIN	# of Counselling hrs for caregivers in the entire GTA (including TC-LHIN)
Total of 3,800 counselling hours provided for the entire GTA	Up to 5 AST Counsellors to provide a total of 1,000 hours of counselling to caregivers living within TC-LHIN, and 4,800 hours for the entire GTA	January	162	406
		February	173	432
		March	168	421
		April	139	348.5
		May	176	439
		June	170	425.5
		July	177	442.5
		August	175	438.75
		September	153	383.5
		October	193	481.5
		November	190	474.2
		December (1 <sup>st</sup> to 15 <sup>th</sup> )	85**	213.3**
		<b>Total</b>	<b>1961</b>	<b>4905.8</b>

\*\* Hours calculated for December (1<sup>st</sup> to 15<sup>th</sup>) are projections based on an average taken between January and November 2012.

c. Education hours for family caregivers and SEC/ICT Coordinators

*Objective:* To promote a better understanding of dementia among family caregivers and SEC/ICT Coordinators

*Performance indicator:* Number of education hours provided by counsellors and education staff at AST for family caregivers and for SEC/ICT Coordinators

*Comments:* **AST was extremely successful in this indicator.** A total of 66.55 hours of education sessions, covering a wide range of topics were provided to family caregivers and SEC/ICT coordinators in the East, West and Central regions of the TC-CCAC. More detailed results are available in Section 5.2.

Baseline in Year 2011	Target	Total Education hours by Month			
		Month	Family caregivers	Professionals	Total
4 on site education hours provided in year 2011	25 hours of onsite education sessions provided by AST Counsellors and Education staff for family caregivers and SEC/ICT	January	7.5	0	7.5
		February	0	0	0
		March	0.5	2	2.5
		April	6	2	8
		May	4	3	7
		June	0	0	0
		July	4	0.05	4.05
		August	2	0	2
		September	4	9	13
		October	5	5	10
		November	9.5	3	12.5
		December (1 <sup>st</sup> to 15 <sup>th</sup> )	0	0	0
		<b>Total</b>	<b>42.5</b>	<b>24.05</b>	<b>66.55</b>



d. New caregivers contacting AST and External referrals by AST

*Objective:* To increase local awareness of dementia and dementia services

*Performance indicator:* AST Counsellors will provide system navigation to family caregivers in TC LHIN and link them to services in the community, including the CCAC

*Comments:* **AST was very successful in this indicator.** Partnering with CCAC, AST received 3,173 contacts from new clients and subsequently, AST played a significant role in system navigation and effective use of resources by linking 811 caregivers to community services in 2012.

Baseline in Year 2011	Target	Year-end Data		
		Month	# of new caregivers contacting AST	# of external referrals by AST
3000 new caregivers contacted AST in year 2011	3,000 new clients would have contacted AST and 400 new external referrals would be made by AST to link family caregivers in TC-LHIN to community services	January	396	76
		February	235	91
		March	297	74
		April	302	179
		May	258	177
		June	204	33
		July	256	50
		August	202	20
		September	289	31
		October	338	41
		November	296	34
		December (1 <sup>st</sup> to 15 <sup>th</sup> )	100**	5
		<b>Total</b>	<b>3173</b>	<b>811</b>

\*\* Hours calculated for December (1<sup>st</sup> to 15<sup>th</sup>) are projections based on an average taken between January and November 2012.

e. Hours of Consultation

*Objective:* To improve the quality of care offered to family caregivers for persons with dementia.

*Performance indicator:* Number of counselling hours and consultation hours offered by AST counsellors to caregivers (CCAC clients) and CCAC Coordinators respectively

*Comments:* The AST was very successful in this indicator, and has well exceeded the target for both caregiver counselling and CCAC coordinators consultation hours. More caregivers are receiving much-needed dementia-specific counselling from AST counsellors. Also, CCAC coordinators are taking a more active role in identifying individual complex cases and consulting AST counsellors on specific strategies and approaches.

Baseline in Year 2011	Target	Month	Number of Counselling Hours by Month	
			For Caregiver	For CCAC Coordinators
No formal consultation process exists	75 hours for counselling to caregivers directly referred by CCAC and 75 hours of consultation to SEC/ICT coordinators	January	9.75	9.75
		February	21.75	10.75
		March	39.25	12
		April	19.5	18.75
		May	25.25	7.75
		June	21.9	5.25
		July	22.75	11.75
		August	18.5	6
		September	22.75	3
		October	20.25	3.05
		November	17.25	5.75
		December (1 <sup>st</sup> to 15 <sup>th</sup> )	10.88**	4.26**
		<b>Total</b>	<b>250.28</b>	<b>98.06</b>

\*\* Hours calculated for December (1st - 15th) are projections based on an average taken between January and November 2012.

### 5.1.2 Other statistics

#### a. The Potential Reach of SEC and ICT coordinators

The Senior Enhanced Care (SEC) Program has three teams of coordinators – approximately 60 coordinators in total – who are assigned geographically to cover East, West and Central areas of the TC-LHIN. The average SEC coordinator caseload size falls within an approximate range of 70-80 clients. SEC coordinators discussed AST services with caregivers on average 45 times per caseload. The 14 coordinators on the Integrated Care Team (ICT) cover the entire TC-LHIN, and the average caseload size for an ICT coordinator falls between a range of 30-40 clients. Since ICT coordinators target medically complex clients, not all clients have dementia. However, AST services are discussed and presented to all clients with dementia (even those with symptoms in very early stages or those with no diagnosis). Information regarding caregiver support programs is provided to them as well.

#### b. Number of AST Information packages distributed

Information packages are educational tools compiled and distributed by AST. Each package contains pamphlets and reports on Alzheimer’s disease and its progression, medications, information on approaches to care, calendar of events, and AST communications. Packages may be sent by post or e-mail.

After the initial call from an AST counsellor, a *First-Link* referral client may decide to receive an information package compiled by AST. As seen in the table below, a total of 819 packages were sent to *First-Link* referral caregivers (up to December 15, 2012). Packages may also be given to SEC/ICT coordinators as per request and/or handed out at AST events (e.g. caregiving education session, presentations and workshops). As of December 15, 2012, a total of 1243 have been distributed by AST to CCAC (this number includes the packages sent to *First-Link* referral clients) and while 18,962 packages have been sent in the entire GTA.

Month	# of packages sent to <i>First-Link</i> referral clients	Total # of packages distributed by AST to CCAC (includes those sent to <i>First-Link</i> referral clients)	# of packages distributed in the entire GTA
January	77	727	1421
February	64	167	1242
March	37	42	1859
April	74	38	1647
May	53	36	1447
June	69	7	1906
July	79	29	1160
August	48	34	1240
September	108	28	2191
October	87	47	1957
November	87	34	2068
December (1 <sup>st</sup> to 15 <sup>th</sup> )	26	54	824
<b>Total</b>	<b>819</b>	<b>1243</b>	<b>18962</b>

#### c. # of Crisis Placements from SEC Community Programs (Fiscal 2011/12)

This information may not be meaningful without an established baseline. Also, variables or factors other than the AST/CCAC inter-professional project may be responsible for any changes and trends in crisis placement data.

Team	Jan 12	Feb 12	Mar 12	Apr 12	May 12	Jun 12	Jul 12	Aug 12	Sep 12	Oct 12	Nov 12
Senior Enhanced Care - Central	9	1	3	1	2	3	4	3	3	6	4
Senior Enhanced Care - East	0	2	3	0	1	2	7	4	6	4	4
Senior Enhanced Care - West	3	5	4	1	0	1	1	3	6	2	4
<b>Total</b>	<b>12</b>	<b>8</b>	<b>10</b>	<b>2</b>	<b>3</b>	<b>6</b>	<b>12</b>	<b>10</b>	<b>15</b>	<b>12</b>	<b>12</b>

Source of Data: Toronto Central Community Care Access Center

## 5.2 Education Sessions for Family Caregivers and SEC/ICT Coordinators

Education sessions were provided to family caregivers and SEC/ICT coordinators on a variety of topics related to dementia according to their different needs, and were found to be beneficial to the two populations of audience.

### 5.2.1 CCAC Sessions Improve Coordinators' Dementia-specific Knowledge & Confidence in Care Management

A total of 24.5 hours of education were provided to SEC/ICT coordinators in 2012. Of these, eight (8) sessions were formally evaluated, by asking coordinators to complete surveys before and after the sessions. 92 SEC/ICT coordinators attended these 8 sessions. All evaluated sessions were 2 hours long except for the special half-day (3 hours) Education Event held at the AST in November. Sessions less than 29 minutes were not formally evaluated.

Educational needs of the SEC/ICT coordinators were assessed 1) in January and 2) again in September. A total of 72 SEC/ICT coordinators from East, West and Central TC-CCAC participated in the needs assessment to determine their self-perceived knowledge about dementia care, confidence to provide dementia care, and interests in attending education sessions hosted by AST. SEC/ICT coordinators also wrote down the topics that they would like to learn about at the education sessions. A copy of the survey is attached in Appendix B1.



At the end of the education session(s), coordinators were asked again to rate their knowledge level regarding dementia care, confidence to provide dementia care, and importance in attending education sessions hosted by AST. They were also asked to fill out a separate survey to provide session-specific feedback. Copies of these surveys may be found in Appendices B2 and B3 respectively.

Results from the first (January-June) and second (July-December) halves of year 2012 are presented below in sections 5.2.1.1 and 5.2.1.2 respectively. In summary, the values of these sessions lie in the **professional exchange and/or discussion of practical knowledge and skills related to dementia care** (e.g. communication and behavioural strategies). Participation in education sessions led to self-perceived improvement in SEC/ICT coordinators, in the following areas:

- **Knowledge** about dementia care
- **Confidence** in providing effective and person-centred dementia care
- Awareness of the **importance in receiving dementia-specific training**

Also, AST was successful in implementing the recommendations from the project's mid-year report, which is, to offer more education sessions to SEC/ICT coordinators in the second half of the year. A total of **SEVEN (7) education sessions** were provided to 82 CCAC coordinators in September, October and November. The lunch-and-learn sessions were well-attended due to:

- 1) Client Services Managers' effort in promoting the sessions to their staff, and
- 2) AST's flexibility in accommodating SEC/ICT coordinators' busy schedule and in sending their Public Education Coordinators (PECs) and AST counsellors to CCAC offices to present to CCAC coordinators.

Another success was the half-day education session held in November. AST took the initiative in conceptualizing, planning and hosting the event. It was carefully crafted to suit the educational needs of SEC/ICT coordinators, and was received positively. The 3-hour session allowed SEC/ICT coordinators to actively participate in **simulation, case study and focus group discussions**.

#### 5.2.1.1 Mid year (Jan-Jun) findings from the SEC educational needs assessment and post-session surveys

As the project commenced in January 2012, a needs assessment was conducted with 39 SEC coordinators from East, West and Central TC-CCAC. 93% of these SEC coordinators surveyed have a caseload of 10 clients or more with dementia, with some coordinators managing as many as 80-90 clients at one time.

Topics that SEC coordinator would like to learn about at education sessions include:

- Knowledge about different types of dementia and their symptoms
- Different types of treatment and therapy for dementia
- Pharmacological versus non-pharmacological management of dementia
- Different day programs and what they can accommodate (behaviours)
- Assessing capacity for borderline clients
- Coping strategies for caregivers
- Strategies of discussing advanced care planning with caregivers
- Long term care options for dementia
- How to manage end-stage/palliative stage of dementia in the community

The coordinators also rated themselves in their dementia knowledge base, confidence in care management, perceived importance in getting dementia-specific training. These attributes were then assessed again after the SEC coordinators attended an education session titled “Alzheimer’s 101” in April. The following table shows the weighted average scores from the pre-session survey and post-April session surveys administered to SEC coordinators. **The results show a self-perceived improvement in knowledge related to dementia care and confidence in care management after SEC coordinators’ participations at AST education session(s).**

Weighted average scores	Pre-session in Jan	Post-April sessions
Knowledge about dementia care	6.55	7.60
Confidence in providing effective and person centred dementia care	6.92	7.90
Importance in receiving dementia specific training	9.61	9.60

All (100%) participants agreed that the education session was “Very helpful” or “Extremely helpful”. They are also satisfied with the organization, content, and clarity of the presentation. Participants noted that education session provided an opportunity to learn new and review old facts about the disease, and strategies for disease and behavioural management. SEC coordinator can bring this knowledge into their practice (i.e. during assessment of caregiver/family). Lastly, all (100%) participants would recommend the training session to others.

#### 5.2.1.2 July-Dec findings from the CCAC educational needs assessment and post-session surveys

From July to December, AST was successful in implementing the recommendations from the project’s mid-year report, which is, to offer more education sessions to SEC/ICT coordinators in the second half of the year. A total of 7 education sessions were provided to 82 CCAC coordinators in September, October and November.

Before these education sessions in the Fall, a second need assessment was conducted with 32 SEC/ICT coordinators from East, West and Central TC-CCAC for the same purposes listed for the first half of the project. This time around, 93% of the CCAC coordinators surveyed have a caseload of 2 or more clients with dementia, with 43% managing the care of 10 or more clients with dementia. Desired topics of discussion are similar to those identified in the first half of the year:

- Strategies for supporting families
- Pre-planning with families in the end stages (palliative support)
- Perspectives of the AST on dementia
- Recent advances and approaches to dementia care
- Dealing with caregiver stress

The AST answered to CCAC coordinators’ educational needs by hosting sessions in the following topics:

- Communication strategies – communicating with families and Communicating with a person with dementia
- Behaviour Strategies – PETA; ABC and 3Rs

- Dementia Research – dementia statistics and different types of dementia
- Resources related to dementia care – UFirst! Tool and Toronto Dementia Network
- Interactive approach – simulation; case study and focus group discussions

Similar to the first half of the year, coordinators rated themselves in their dementia knowledge base, confidence in care management, perceived importance in getting dementia-specific training BEFORE and AFTER the education sessions. The weighted average scores from the pre-session survey and post-Sept, Oct and Nov sessions surveys administered to SEC/ICT coordinators show that **self-perceived improvement in knowledge related to dementia care and confidence in care management was consistent in CCAC coordinators following their participation at AST education session(s):**

Weighted average scores	Pre-sessions (Needs assessment)	Post-September sessions	Post-October sessions	Post-November Education Event	Weighted Averages for all post-sessions in the Fall
Knowledge about dementia care	6.61	7.14	7.31	7.17	7.23
Confidence in providing effective and person centred dementia care	6.65	7.35	6.91	7.33	7.13
Importance in receiving dementia specific training	8.97	9.14	9.06	9.33	9.12

The majority (96.5%) of participants agreed that the Education session was helpful. They are also satisfied with the organization, content, and clarity of the presentation. These sessions also provide participants the opportunity to:

- learn to provide client-oriented care by keeping an open mind and spending more time to listen,
- become more sensitive to cultural needs of clients,
- review facts about the disease, and strategies for disease and behavioural management, and
- learn about and subsequently advocate for AST resources and services (e.g. *First-Link* Referral)

### 5.2.2 Caregivers Sessions

As part of the collaboration, and to improve access to dementia education and information for family members, AST hosted five education sessions for family caregivers caring for individuals with dementia at home. Some sessions were also held at various TC-CCAC offices. The following topics were covered:

- The Dilemma, Pros and Cons of Placement; Caregiving Options; Assessing a facility (series of 3 sessions).
- Discussion on Placement; Preparing for the Move; Day of Placement; Adjustment.
- Exploring together what can improve the quality of life for the person with Alzheimer Disease and other dementias and their caregivers in Long-Term care.
- Overview of Dementia; Understanding Why Behaviours Occur; Communication; Ways of Dealing with Behaviour; Supportive Services

A total of 40 caregivers attended the above sessions. More than 90% of those in attendance were adult children caregivers. In all cases, participants were completely satisfied with the organization, content, and clarity of the sessions. Participants especially appreciated the opportunity to share their experience with others. Hearing others' stories help caregivers realize that they are in a supportive community.

### 5.3 Positive Impacts of the Inter-professional Partnership on Family Caregivers

#### 5.3.1 Who made referrals to AST?

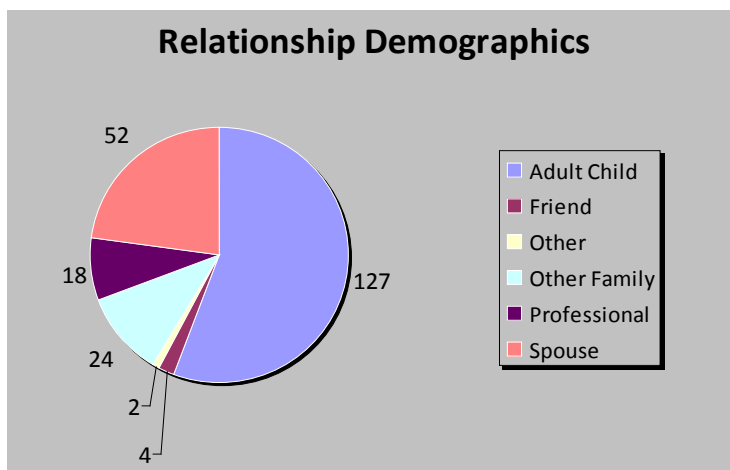
A total of **227** *First-Link* referrals were received at AST in 2012. The average age of those referred is 63.4. Primary languages spoken by them are as follows:

Language	Percentage
English	94%
Greek	3%
Portuguese	1%
Cantonese	1%
Italian	1%
Other	1%

As seen from Figure 5.1 below, 55.9% of the 227 *First-Link* referrals to AST were by adult children of persons with dementia and 22.9% were from spouses. Other referral sources included:

- Other family – includes daughter or son in law, grandchildren, aunts or uncles,
- Professional – persons in charge of cases relations to PWD (e.g. CCAC coordinators and/or case workers),
- Friend – self-identified friend of PWD, and
- Other – anyone not fitting into any of the above relationship category (e.g. concerned neighbour)

**Figure 5.1 Relationship demographics of family caregivers contacting AST**



Source of Data: Alzheimer Society of Toronto

#### 5.3.2 Contacts by Relationship and Service Types

To further explore which group requires the most attention, data analysis was performed to provide a breakdown of contacts by relationship. As seen in Table 5.1, spouse caregivers required more multiple interventions (i.e. using a combination of AST services) than filial caregivers. Majority of referrals from Professionals and Friends are single contacts to AST, and were inquiries about AST services and requests for information packages. Some may become on-going clients later on as the disease progresses.

**Table 5.1 Number of contacts by relationship**

Relationship	1 contact		2-4 contacts		≤ 5 contacts		TOTAL
	Number	Percent	Number	Percent	Number	Percent	Number of Contacts
Child	90	50.8	65	36.7	22	12.4	177
Spouse	21	39.6	26	49.1	6	11.3	53
Other Family	12	44.4	12	44.4	3	11.1	27
Professional	12	70.6	5	29.4	0	0	17
Friend	5	83.3	1	16.7	0	0	6

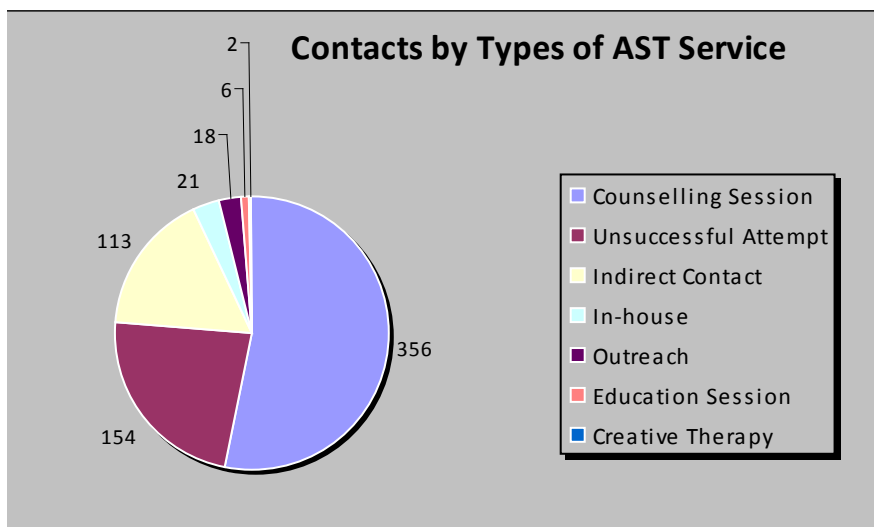
Source of Data: Alzheimer Society of Toronto

To understand how the referrals are followed up, these contacts were categorized by service types. Below is a brief description of these services:

- Counselling sessions – Telephone-based sessions with AST counsellors
- Indirect Contact – Contacts made with Professionals from any external agency (including CCAC coordinators) in the absence of referral source/PWD
- In-house – Office Visits
- Outreach – Counselling sessions done via outreach visits or external clinics
- Unsuccessful Attempt – Attempts made by counsellors to contact Callers that were unsuccessful, and resulted in a left message or no contact
- Education Session – Educational workshops facilitated in-house (i.e. Alzheimer 101)
- Creative therapy – Creative Therapy facilitated in-house (i.e. Nia)

The use frequency of the above service types is represented as a pie chart in Figure 5.2. As seen in the figure, **53.1% of the calls are followed up by counselling sessions provided by AST.**

**Figure 5.2 AST services requested by referred clients contacting AST**



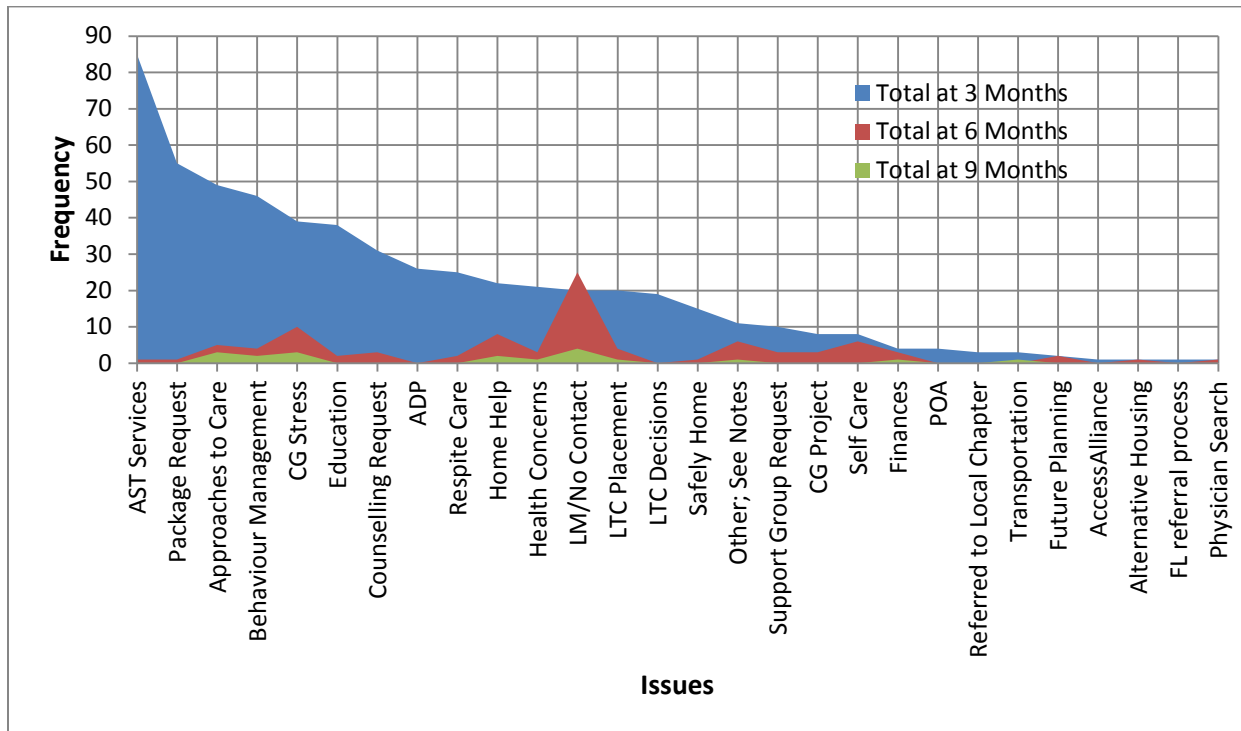
Source of Data: Alzheimer Society of Toronto

### 5.3.3 What issues are being discussed at the Counselling Sessions?

Caregivers who were referred to AST discussed a large array of issues with the AST counsellors. There are slight differences between spousal and filial caregivers in the topics discussed. Filial caregivers tend to need more guidance regarding behavioural management, caregiver stress and approaches to care than spousal caregivers. On the other hand, spousal caregivers focus on LTC decisions and home help.

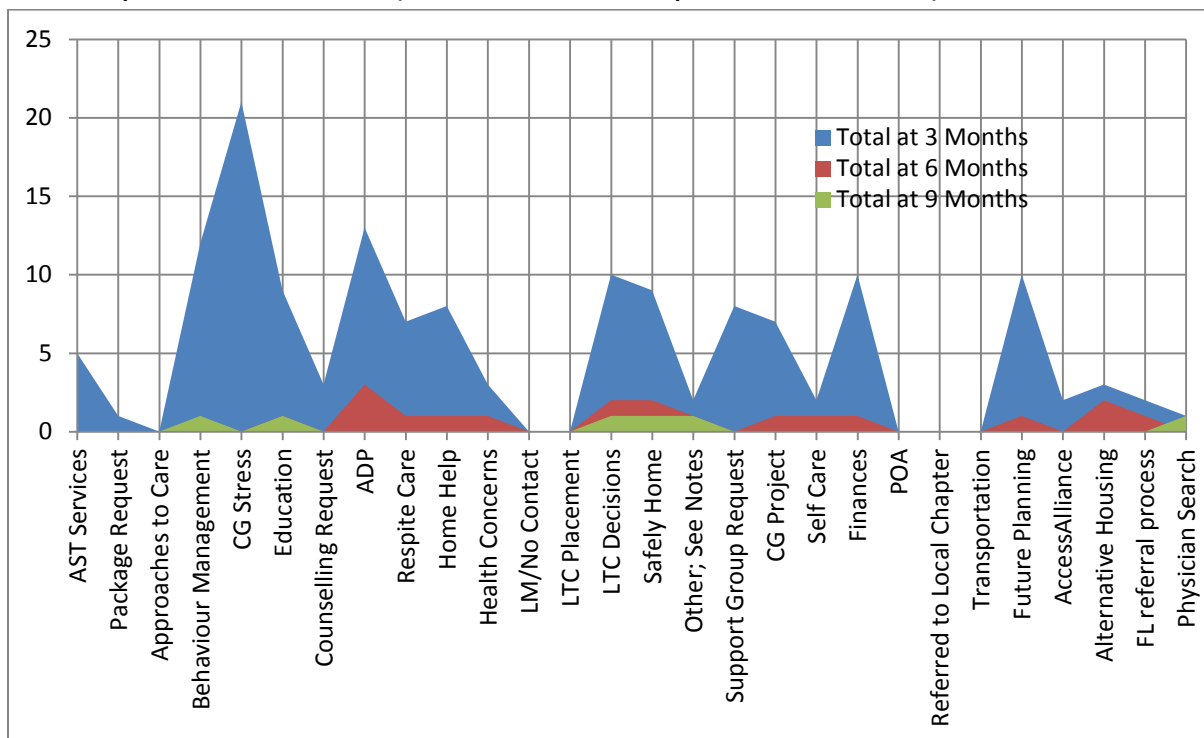
Figure 5.3 shows a wide range of topics that were discussed between the AST counsellors and the caregivers. (legends in APPENDIX C). Figures 5.4 and 5.5 display the issues discussed by spouses and adult children respectively, at 3, 6, and 9-months follow up. As observed from these two charts, both initially and over time, spouses on average had more issues to discuss than adult children. Adult children had a 43% decrease in issues discussed per average phone call, while spouses had only a 31% decrease. Thus, it can be suggested that overtime, adult children require more focused help on specific issues than spouse.

**Figure 5.3 Frequency of issues discussed between AST counsellors and all Caregivers contacting AST and followed up at 3, 6, and 9 months. (Total number of issues up to Dec 15, 2012 = 681)**



Source of Data: Alzheimer Society of Toronto

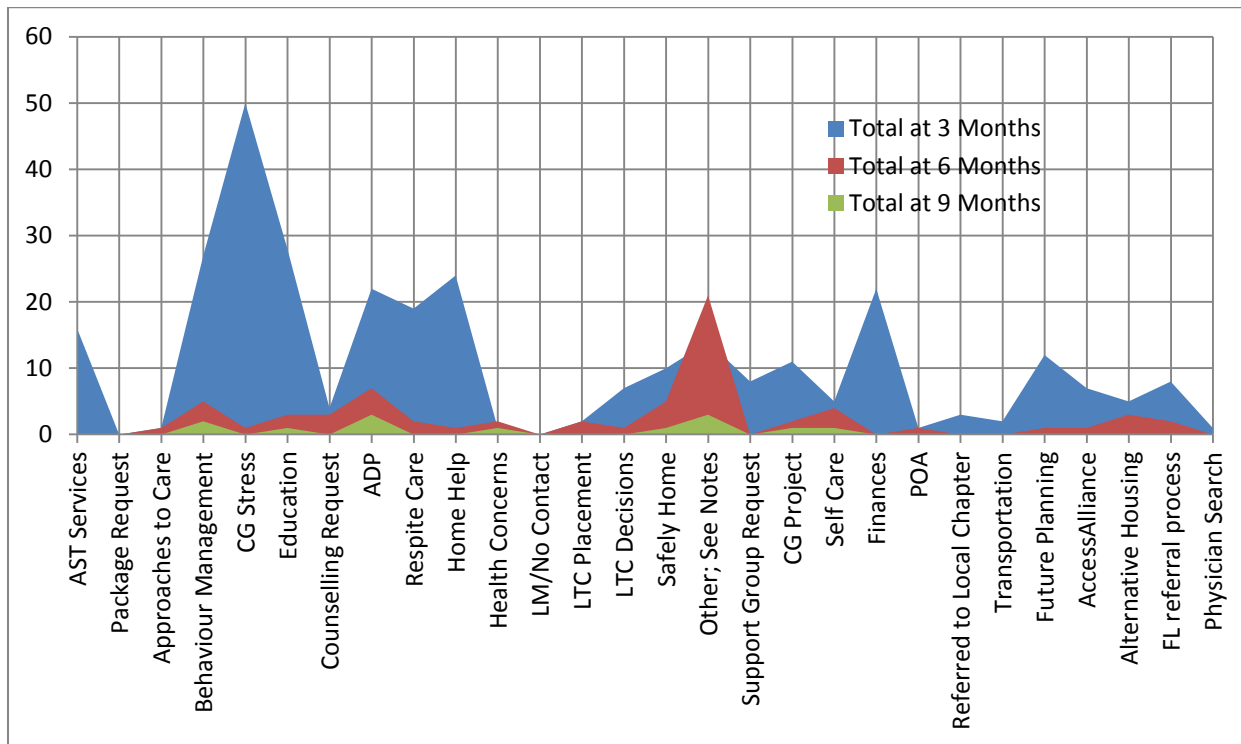
**Figure 5.4 Frequency of issues discussed between AST counsellors and Spousal Caregivers contacting AST and followed up at 3, 6, and 9 months. (Total number of issues up to Dec 15, 2012 = 173)**



Source of Data: Alzheimer Society of Toronto



**Figure 5.5 Percentage of Issues discussed between AST counsellors and Filial Caregivers followed up at 3, 6, and 9 months. (Total number of issues up to Dec 15, 2012 = 391)**



Source of Data: Alzheimer Society of Toronto

### 5.3.4 AST/CCAC Collaboration was effective in Ameliorating Caregiver Stress

All caregivers referred by CCAC to AST would fill out a *First-Link* referral form upon initial contact with the AST. Distress level of each caregiver was assessed by asking two questions: 1) On a scale of 0 to 10, how confident are you in providing care? 2) On a scale of 0 to 10, how stressed do you feel regarding your caregiving role?

Follow-up calls were subsequently made to the referred clients at 3, 6 and 9 months after the initial contact/intervention to assess the same constructs. As seen in Figure 5.7 below, stress level was decreased and confidence in providing care was increased in referred clients. The improvement was even more prominent in filial caregivers (Figure 5.8), who were more inclined to request counselling surrounding caregiver stress, behaviour management, or approaches to care.

Figure 5.7 Changes in confidence and stress level in *First-Link* referred caregivers at 3, 6, and 9 months

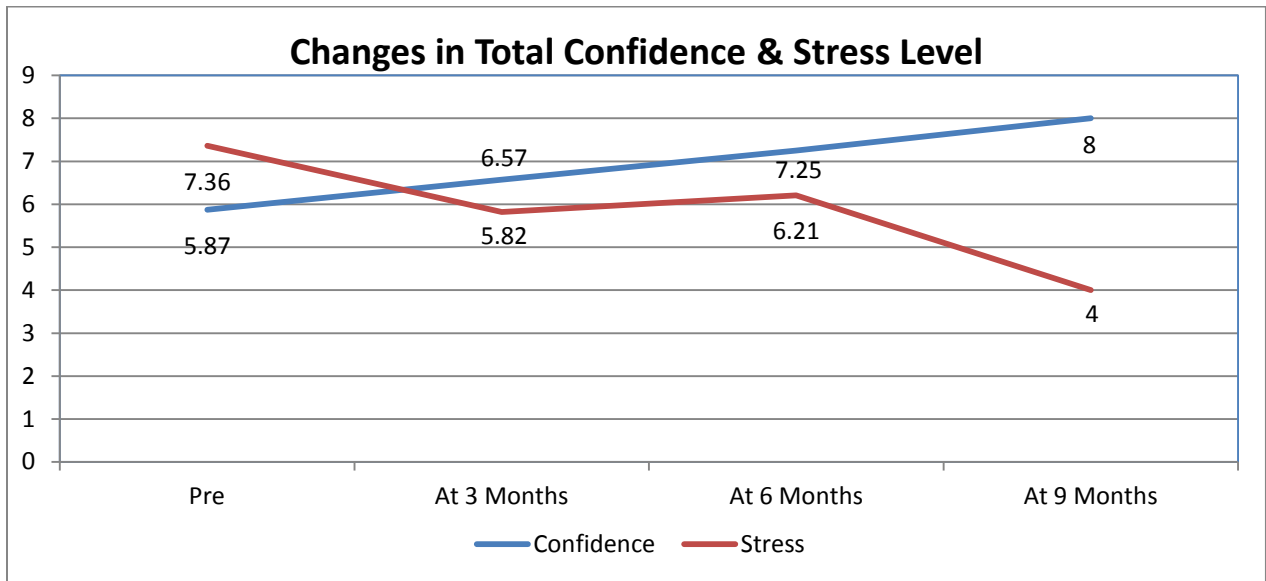
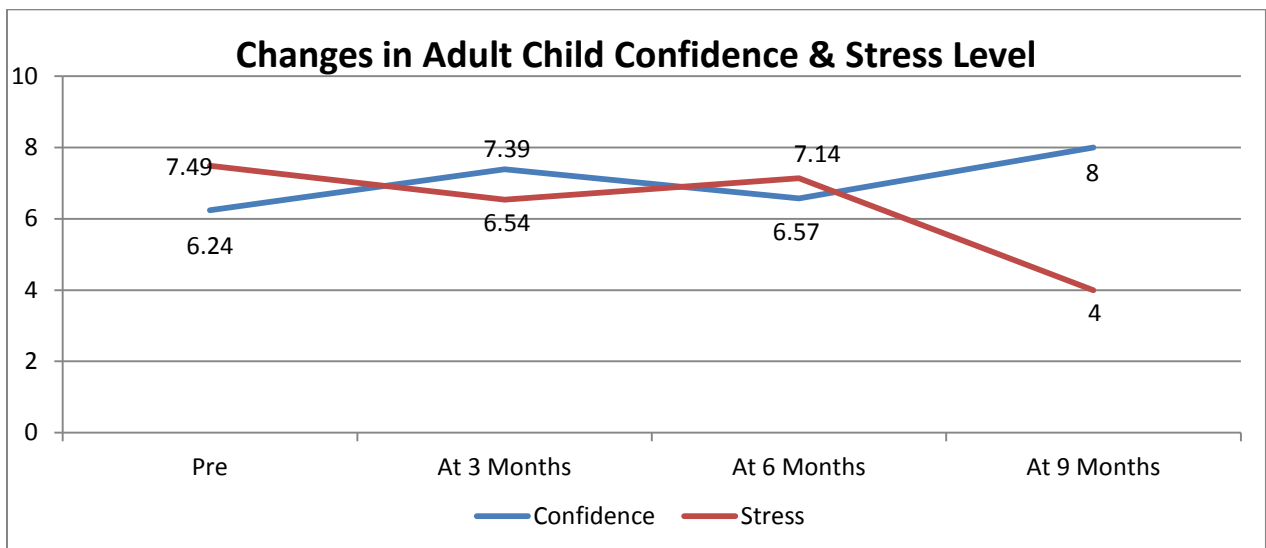


Figure 5.8 Changes in confidence and stress level in *First-Link* referred filial caregivers at 3, 6, and 9 months



#### 5.4 Feedback from Staff

Nine CCAC coordinators and all five AST counsellors participated in separate focus groups in November 2012 to discuss their role, and the barriers and facilitators that they perceived for the inter-professional collaboration. Both focus groups discussions were facilitated by Mary Chiu, the project evaluator. Common themes that arose from the two focus groups are summarized below. These themes are supported by quotes extracted from the focus groups transcripts.

#### Complementary Roles

As both groups discussed how they contribute to the inter-professional collaboration, it became clear that **AST counsellors and CCAC coordinators take on different approaches in providing support to dementia caregivers, but complement each other well in their roles.** CCAC coordinators see themselves as “facilitators” as they facilitate the relationship between the caregiver/family and the AST. AST counsellors are more involved in providing in-depth and intensive dementia-related counselling to caregiver/family.

AST counsellors	CCAC coordinators
<ul style="list-style-type: none"> <li>• Wealth of knowledge in dementia care and emotional support</li> </ul>	<ul style="list-style-type: none"> <li>• Have immense expertise in community work</li> </ul>
<ul style="list-style-type: none"> <li>• Provide in-depth and intensive dementia-related counselling, support in behavioural management, education in the adjustment process</li> </ul>	<ul style="list-style-type: none"> <li>• Provide system navigation to clients: gauging caregivers’ interests and level of comfort before referring them to different sources and formats of information</li> </ul>
<ul style="list-style-type: none"> <li>• Support caregivers emotionally in decision making</li> <li>• Refer clients internally to other AST programs e.g support groups and externally to other community services e.g. ADP</li> </ul>	<ul style="list-style-type: none"> <li>• Introduce clients to AST for the first time and ensure warm transfer of the clients</li> <li>• Explain AST services to caregivers: Some services are being widely utilized already (e.g. Safely Home registry), while others may not be well-known (e.g. one-on-one counselling and education workshops)</li> </ul>

- CCAC coordinators acknowledged that the partnership is extremely valuable to them as AST helps them **improve their knowledge base of the disease:**

*“As a CCAC staff, it is difficult for us to know everything there is about everything, including dementia, because there are just so many aspects to our work. It is very helpful to have specialists on hand to talk to or consult with regarding clients with needs surrounding Alzheimer’s.” – SEC coordinator*

- It is also comforting to know that they have **a rich resource base to draw on** as they offer dementia information and support to caregiver and family:

*“We are in the community every day, we are seeing families. The fact that we have this partnership allows us to introduce AST to the family and expand the range of services that is available to them that can be easily accessed.” – SEC coordinator*

*“There is this feeling of being overwhelmed as CCAC coordinators... the needs of the caregivers have, the needs of persons with dementia have... and not knowing what to offer can be stressful. This (AST) is a great resource.” – SEC coordinator*

- On the other hand, **AST counsellors appreciate the increased awareness of AST services**, propelled by the continuous effort that SEC/ICT coordinators put in to referring appropriate clients to AST.

*“Definitely the referral numbers have gone up. There is an increased awareness about what AST does, by the coordinators and the caregivers, and coordinators are more inclined to consider AST services in their case management for their clients.” – AST counsellor*

- **AST counsellors also enjoy the working relationship with the SEC/ICT coordinators.** Coordinators can provide counsellors with important background information on a particular client, allowing counsellors to offer the client more specific and effective interventions.

*“AST outreach visits to clients are sometimes done together with care coordinators. It was very helpful to learn from them (coordinator) directly what they have already done and/or provided in a particular case, as the caregivers may not be able to provide the full background. With the information and/or interaction (with the coordinator), we (counsellors) can provide more relevant suggestions and support” – AST counsellor*

### **Enhanced Communications Led to Meaningful Partnership**

Effective communication improved the working relationship between AST and CCAC. At the beginning of the project, AST Chief Program Officer Marija Padjen attended SEC/ICT team meetings and explained to SEC/ICT coordinators the inter-professional project, the expectations from both AST and CCAC, and the services that AST provides (e.g. one-on-one counselling on the phone, education workshop, *First-Link* referral). Significant time was spent on building a strong foundation for the relationship between these two organizations and to improve communication and knowledge transfer. Managers and direct service staff (i.e. counsellors and coordinators) made a concerted effort to ensure this happened.

This heightened awareness of AST services was maintained through regular e-mail communications and reminder at CCAC team meetings. Subsequently, AST services have become part of the list of services that care coordinators would refer to during a caregiver assessment.

CCAC coordinators appreciate the close working relationship fostered as a result of the project. AST counsellors would follow up with SEC/ICT coordinators with a call after talking to a SEC/ICT-referred caregiver. SEC/ICT coordinators are informed of the caregivers’ next steps. For example, a caregiver may continue to use AST services such as workshops or counselling sessions. Sometimes caregivers may decline any further services other than receiving the information package. Having this feedback is helpful for SEC/ICT coordinators as “It’s like closing a loop”.



The enhanced communications also allow for the inter-professional relationship to flourish. Counsellors and coordinators take advantage of all opportunities to learn about each other’s work culture, functions and approaches to client care. Education events hosted by AST provide **an alternative forum for idea exchange**.

*“Besides learning from the planned presentations (during the education sessions), I also appreciate the opportunity to exchange ideas, to identify more effective ways to collaborate, to develop rapport and meaningful relationship with my colleagues at AST and CCAC.”  
– SEC coordinator*

**At the leadership level, CCAC Client Service Managers meet monthly with the AST Chief Program Officer,** to internally evaluate the progress of the project, and strategically plan the next steps. This dynamic and iterative approach to planning allows the leadership team to be in tune with the way the project progresses, to make adaptations based on lessons learned so far, and to plan future events accordingly.

### **Flexibility and Responsiveness of AST staff and counsellors**

1. User-friendly *First-Link* referral form and flexible referral process: In the past, information was given to caregivers and they would have to contact AST themselves. Often overwhelmed, caregivers would not follow up

with AST. With the *First-Link* referral process, SEC/ICT coordinators find it very rewarding in helping family make that extra step, going through with the referral. Also, the *First-Link* referral form is quick and easy to fill out. Offering to make the referral on the family's behalf is easy for SEC/ICT coordinators since the form and process is user-friendly. AST staff and counsellors are flexible in accommodating referrals that came in as a phone call (e.g. when coordinators are in client's home or "on the road"), by filling out the *First-Link* form on behalf of the SEC/ICT coordinators as the coordinators provide details of the clients.

2. The responsiveness of AST counsellors: SEC/ICT coordinators commented on how beneficial it is to have counsellors ready to help clients who are ready (i.e. AST counsellors "can jump into their (caregivers') readiness")

*"Having the one-on-one counselling right there, that they can phone in right at the moment when they are dealing with a crisis, is also a great thing. That's when family members would use the service and a couple of hours later follow up with the coordinator on how the AST counselling went." – SEC coordinator*

### **Positive Impacts of the AST/CCAC Partnership on Caregivers and Seniors being Referred:**

**1. Building a strong support system that caregivers can access and rely on:** The partnership allows caregivers easy and quick access to a wide range of relevant services. It also improves the **depth of care available to AST caregivers and family**. More importantly, caregivers may choose to utilize services that they are comfortable with. Education sessions further allow caregivers to generate relationships through non-intrusive means that are initiated by the caregivers themselves.

*"Care coordinators may get bogged down by the practicalities of what's going on. Partnership is valuable for both the dementia caregivers and the coordinators as they are made aware of the services that's available to them that's specific to their needs" – AST counsellor*

*"Providing caregivers with a direct number, with a counsellor's name, at the early stages allows for relationship to be developed and rapport to be built. The caregivers are more inclined to pick up the phone and call when they need help." – AST counsellor*

**2. Building clients' trust and confidence in a collaborative system:** When several units or health professionals "working in silos" try to provide support, there is a greater possibility for confusion. Subsequently, clients would be less likely to access services. In this project, caregivers really appreciate the seamless approach in their care provided by AST and CCAC. The linkage between AST and CCAC is clear and simple, and the warm transfer of clients between the two organizations was ensured.

*"When we follow up with the caregivers, notifying them that they have been referred by a CCAC coordinator, caregivers become confident that the system is trying to wrap around them and to be responsive to their needs. This subsequently encourages engagement." – AST Counsellor*

**3. Ensuring client-centred care management:** The partnership provided support with a focus on clients' needs and wants thereby ensuring flexibility and not just conformity to the status quo.

*"Brainstorming often happens between the AST counsellors and CCAC coordinators in search for the most appropriate support for the clients, by considering their background and what they already had access to."*

**4. Adding "balance" to care management of clients:** Getting different perspectives from health professionals was beneficial to the caregivers.

*"Clients have another professional from whom they can seek advice. It's like getting a 'second opinion'. AST counsellors play an important role in reinforcing whatever information that care coordinators have been trying to tell their clients." – SEC coordinator*

*"Including people with expertise in dementia means caregivers get another perspective. This adds balance to the case." – SEC coordinator*

**5. Managing and counselling family as a unit:** Conflicts are common amongst family members of a person with dementia, as some family members may find it difficult to come to terms with the diagnosis. For example, after a diagnosis of dementia, a particular adult child may be very active and would get involved while another child might be in denial. Also, role of primary caregiver usually falls on the adult child who lives closest to the dementia parent. AST and CCAC are successful in providing support and education to the family as a whole, helping to resolve some of these conflicts.

*“When the whole family is involved in care management and education, difficult discussions may be better facilitated.” – SEC coordinator*

*“Adult children may have a difficult time convincing one of their parents that they needed extra help in caring for the other parent who has dementia. Capacity assessment, when performed by AST and CCAC, make it easier for caregivers to accept that they may not be capable in managing.” – SEC coordinator*

**6. Providing emotional support to clients:** SEC/ICT coordinators acknowledged the fact that they may not have the time and resources to provide the much needed emotional support to the clients. Counselling provided by AST, therefore, is a good resource to draw on when caregivers encountered difficulties with regard to burden, stress, or adjustment.

*“Having more support for the caregiver is essential. We (CCAC coordinator) may not have the time or resources to offer counselling for the caregiver. This is when AST steps in and this gives caregivers another great sounding board (other than their CCAC coordinator).” – SEC coordinator*

*“AST counsellors have a huge role in supporting caregivers in making important decisions such as moving a loved one into LTC. We provide a lot of education and support in the adjustment process. Another example would be introducing a PSW into the home – it can be a huge thing for a lot of people. AST is there to support the caregivers emotionally” – AST Counsellor*

*“Counselling is extremely beneficial to caregivers as it helps to normalize feelings that caregivers are experiencing.” – AST counsellor*

**7. Meeting education needs:** Caregivers often lack education regarding Alzheimer’s disease and other dementias, and misconceptions may arise, leading to stress as they struggle to make sense of the situation. When these clients are referred to AST, they attend education sessions to learn about the disease, its progression and management. In turn, their confidence and stress level improve.

*“In certain cultures, people don’t accept that Alzheimer’s disease as a medical condition. They see it as a defect. They don’t have the education (around dementia). That doesn’t only put them at risk but also the person they are taking care of, as there would be a lot of misunderstanding and anger involved.” – AST counsellor*

**8. Reducing stigma and cultural barrier:**

- Stigma around dementia – dementia is perceived differently by different cultures. Some ethnic groups may be hindered from accessing education materials and other AST programs. AST attempts to be as inclusive as possible and reach out to all ethnic groups, by hiring counsellors of different ethnic backgrounds, and using interpretation services such as *Access Alliance*. Through the partnership with CCAC, the goal is to advocate and promote dementia education and to encourage other agencies to be more inclusive.
- Stigma around Long term care home (LTCH) placement – In certain cultures, there is a stigma that is associated with putting someone into a LTCH. Caregivers may be very hesitant in admitting family members to LTCH. There is a lot of guilt associated with starting a referral, or even considering LTCH for a family member.
- AST counsellors are experienced in mitigating stigma around dementia and were readily accessible by phone to address caregiver concerns about placement. As seen in Section 5.2, AST provides education sessions to Caregivers to “demystify” the LTCH referral decision, application process, and admission. These sessions are held in conjunction with the Placement Coordinator Manager from the CCAC. AST will

also continue provide consultation and education to CCAC coordinators, helping them guide their clients in the right direction regarding making this important decision and step in caregiving.

- **Inclusivity in service delivery and increased awareness around stigma and are key strategizes as the AST/CCAC collaboration continues.**

### ***Suggestions as AST and CCAC look forward to continuous collaboration***

**1. Reciprocal exchange of knowledge** – AST counsellors are especially interested in learning about the updated overview of what CCAC offer, as their teams and community resources may differ across Toronto.

*“There have been lots of opportunities for CCAC to participate in education sessions and workshops hosted by AST. We are interested in learning from CCAC as well, as they are an organization that’s constantly changing” – AST counsellor*

**2. Refer appropriate clients to AST early and often** – both AST counsellors and SEC/ICT coordinators believe that building a strong structure of support for their clients now may prevent crisis situations in the future. The benefit of building a relationship between AST and caregivers at the early stages is that there would be a wider range of services that counsellors may refer caregivers to, which would support them better. Also, with an established relationship, caregivers would be more inclined to reach out to AST when help is needed.

*“With more advanced stages of dementia, the challenge is that there are limited services that counsellors may refer the caregivers to.” – AST counsellor*

*“The premise of the counselling program is prevention of crisis cases. Even if caregivers are already putting all the practical steps in place, that doesn’t mean that referral to AST is not needed. CCAC coordinators may realize that there is still room for the linkage (between CCAC and AST) in these ‘early stages.’” – AST counsellor*

*“Clients may not be ‘ready’ then, but you have initiated the dialogue and introduced AST as a possible resource” – SEC coordinator*

*“Before the partnership, I seldom thought of the AST as a resource. I’m so focused on, I’ve got to complete the assessment, or what types of home care can I offer? I was very narrow-minded. Now, with the partnership more established and visible, it’s becoming second nature for me to talk to clients about AST.” – SEC coordinator*

**3. Providing education around stigma and cultural sensitive counselling and support for family members** – As mentioned above, it is important be inclusive to marginalized and ethnic cultural groups as this AST/CCAC partnership continues. AST and CCAC will continue to work closely to provide family caregivers education and counselling, to mitigate stigma around dementia and to emotionally support them through adjustments processes.

## Section 6 Success Stories

Two cases are presented here to demonstrate how effective interactions and communications between AST, SEC/ICT coordinators and caregivers may improve the quality of services provided to caregivers and persons with dementia. *\*\*Names have been changed.*

**CASE A:** *This case shows how the collaboration was able to provide multiple intervention strategies for a daughter with severe medical issues caring for her mother in the latter stages of dementia at home.*

Allison, a counsellor at the Alzheimer Society of Toronto, received a First Link referral from a SEC Coordinator, James. The client was a middle-aged daughter with severe health issues, caring for her mother with Lewy Body Dementia at home with CCAC support. At the time of referral, the clients stress level was marked as very high.

After a brief phone assessment, the counsellor set up an office visit with the daughter. Issues around self care and were discussed at great length and the client was referred internally to the monthly Lewy Body Family support group as well as to external services. A call was made to the SEC



Coordinator to discuss the initial assessment and recommendations. The SEC Care Coordinator continued to work with the family to establish an on-going care plan and support the family as needed.

The daughter began attending the support group shortly after the first visit. She reported the group as being very helpful and supportive. By the following office appointment, the daughter, while still anxious, stated she was feeling better. Issues around Lewy Body Dementia's progression continued to be discussed and in particular palliative care at home. The PSWs working with the family were referred to the Alzheimer Society's Dementia Certificate Program and Palliative Care and Dementia workshop to enhance their knowledge and skill set in dealing with the late stages of Lewy Body Dementia.

**END RESULT:** *In the 8 months since the initial referral, the client continues to meet both individually and in groups sessions with a counsellor. While her own health issues continue, her resiliency has improved and she feels more in control of the caregiving situation and her mother continues to reside in the family home with the support of CCAC.*

\* \* \* \* \*

**CASE B:** *This case demonstrates the benefits of having a AST counsellor and SEC coordinator "walking alongside" a distressed adult child caregiver, and assisting him in navigating the difficulties with care for his mother who has complex needs and behaviours associated with dementia.*

AST received a call from Mr. Newman, a primary caregiver for his mother who has dementia. Mr. Newman was experiencing difficulties in coping with his mother's responsive behaviours including incomprehensive communication. She was also incontinent of bowel and bladder. At the time, 2 Personal Support workers (PSWs) were visiting his mother daily (1 in the morning and 1 in the evening). Mr. Newman's mother was also attending an Adult Day Program, however, he was reluctant to have her return. Mr. Newman was feeling very overwhelmed, but wanted to keep his promise to his father to keep his mother at home and not in a LTCH. It was clear that Mr. Newman needed 1) more information and education regarding Alzheimer's disease and associated behavioural symptoms and 2) support in planning for the future.



The attending counsellor, Nancy, followed up two weeks after the initial call. Mr. Newman again expressed his sense of overload. Issues around incontinence were leaving him exhausted and he **felt helpless in providing care on his own**. He felt his own siblings were not supportive, although his wife and few close friends were helpful to him during this time. Mr. Newman was **interested in having his mother attend a short-stay bed at a *Complex Continuing Care Program (CCC)***. **The AST counsellor invited Mr. Newman to come in for an office appointment to explore the feasibility with this plan.**

At the office appointment, Mr. Newman spoke about his caregiving stress and exhaustion. Nancy helped him in **acknowledging his need to prioritize his own well-being**. Mr. Newman brought up the discussion regarding CCC application again. He was very interested in pursuing this as he was impressed with the level of care. AST Counsellor explained in detail the eligibility criteria of CCC Programs, and focused on helping him broaden his search to include CCC Programs in other areas of Toronto.

After the needs assessment, Nancy consulted with TC-CCAC case manager regarding the process of CCC Programs applications. Mr. Newman's **SEC Coordinator also supported him regarding short term respite for his health**. Mr. Newman was also encouraged to call his local Community Agency to determine if his mother was eligible for the Day Program and the overnight Day Program. At last follow-up, Mr. Newman was in the process of applying to CCC.

**END RESULT: Mr. Newman repeatedly expressed that he was overwhelmed by his role as a caregiver to his mother. During an AST counselling session, it finally became clear to him that his own well-being needed to be taken care of and respite for his mother would be a good solution. AST and CCAC worked collaboratively to introduce and connect Mr. Newman to the resources that are appropriate and available for him. At the time of writing, Mr. Newman's other family members were also contacted by AST in an attempt to involve them in the planning and care of the PWD.**

## Section 7 Recommendations and Conclusions

As mentioned in Section 4.2, a working group of *Canadian Inter-professional Health Collaborative* volunteers provided oversight and advice on the development of a “Canadian Inter-professional Competency Framework”. The framework provides an integrative approach to describing the competencies required for effective inter-professional collaboration<sup>2</sup>.

After one year in operation, it can be concluded that the “Alzheimer Society of Toronto/TC-CCAC Inter-professional Collaboration Project” is a **very successful initiative**, as it aligns extremely closely with all indicators of competency proposed in the CIHC Competency Framework:

1. **Inter-professional communication:** Effective and ongoing communication has been a high priority since the very beginning of the project. Several avenues for communication between SEC/ICT coordinators and AST counsellors were established and maintained: follow-up phone calls on a *First-Link* referral, regular e-mail communications, CCAC team meetings, and informal discussions after an education session etc. At the leadership level, CCAC Client Service Managers meet monthly with AST Chief Program Officer to internally evaluate the progress of the project, and to strategically plan the next steps. As a result, all who are involved in the project can “communicate with each other in a collaborative, responsive and responsible manner”<sup>2</sup>.
2. **Patient/Client/Family-centred care:** The physical, emotional, social and cultural needs of persons with dementia, the caregivers, and the families are valued by AST and CCAC. AST counsellors and SEC/ICT coordinators work collaboratively to seek out and sensitively integrate the input of their clients when making care recommendations and providing support.
3. **Role clarifications:** Both AST counsellors and SEC/ICT coordinators know their role very well, and are clear on what strengths they can bring into the collaboration. Counsellors and coordinators take advantage of all opportunities to learn about each other’s work culture, functions and approaches to client care. They then use this knowledge appropriately and work together to establish and meet clients’ goals.
4. **Team function:** AST counsellors and SEC/ICT coordinators work seamlessly as a team as both groups appreciate the close working relationship fostered as a result of the partnership. The ongoing professional discussion and communication of cases led to better client management and outcomes.
5. **Collaborative leadership:** Personnel at the leadership level both at AST and CCAC meet monthly to review the project progress. The dynamic and iterative approach to planning allowed the leadership team to be in tune with the way the project progresses, make adaptations based on lessons learned so far, and plan future events accordingly. Quarterly touch base meetings between the AST Chief Program Officer and the TC-CCAC Director of Community Programs were held to identify any high level issues or action needed to ensure success for the project.
6. **Inter-professional Conflict Resolution:** Effective inter-professional communication is dependent on the ability of teams to deal with conflicting viewpoints and reach reasonable compromises. This was especially evident at the management level at AST and TC-CCAC, as leaders take constructive steps to address conflicts e.g. a resolving a scheduling conflict to ensure that Care Coordinators from 3 different geographical zones within TC-LHIN can attend important AST education sessions.

### **Improving system and caregiver capacity**

Instead of reacting and responding to arising problems and to alleviate crisis situations, the partnership between AST and CCAC was developed with the objective of preventing crisis from happening in the first place. The idea is to build individualized support systems early on and have care plans established for the clients so that crisis may be averted, taking a proactive approach and thereby mitigating the need for and health professionals to be reactive in working with this client population. As such, the partnership may be the first step towards improving and building system capacity for this client population. As dementia clients and caregivers are referred to and supported through a more integrated approach, close collaboration and communication within the system is made possible and maintained. At the same time, caregiver capacity is improved, as caregivers become confident that

---

<sup>2</sup> *Canadian Inter-professional Health Collaborative* (Feb 2010), “A National Inter-professional Competency Framework.” [http://www.cihc.ca/files/CIHC\\_IPCompetencies\\_Feb1210.pdf](http://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf), accessed on Dec 10, 2012

the system is trying to wrap around them and be responsive to their needs and encourage and support their engagement.

Building on the success of the current project, this inter-professional model may also be adopted by other chapters of Alzheimer Society. More partnerships may be established and maintained between Alzheimer's Societies, CCAC and other initiatives or agencies (e.g. community behavioural support outreach teams). Drawing from each others' strengths and knowledge and working collaboratively in a systematic fashion will have a positive impact at both the individual and system level.

## Conclusions

Previously, the TC-LHIN *Caregiver Framework* demonstration project led by the Alzheimer Society of Toronto (AST) introduced SEC/ICT coordinators to AST in a positive and reinforcing way. The current project further enhances the inter-professional relationship between AST and CCAC. CCAC care coordinators continue to appreciate how education, communication and consultations with AST counsellors build their capacity to support this client population in a more meaningful way. AST counsellors benefit by being perceived as part of the team, through improved communication and increased referrals for counselling and family education.

This is an important partnership to maintain as it:

- Improves access to care and services for dementia clients and their families
- Promotes a more integrated, family-focused system of care to reduce caregiver stress and build caregiver resiliency to sustain the caregiver role
- Demonstrates the benefits of dementia education and emotional support and counselling for caregivers
- Enhances the knowledge and skills of the SEC and ICT coordinators in their case management work with this population.
- Promotes a more proactive approach to supporting clients with dementia and their families/caregivers that may improve quality of care, and prevent or mitigate family crises that can lead to inappropriate visits to ER, overlong stays in ALC and premature placement in long term care.
- Improves communication by embedding AST counsellors with the SEC/ICT teams and provides a more seamless, quick response to client needs
- Allows the development of processes across both organizations that support collaboration and integration

**The AST/TC-CCAC inter-professional collaboration should be continued.** The goal will be to strengthen this successful partnership in an ongoing manner, and to ensure that it is embedded in the culture and processes of each organization. Ultimately, more at-risk caregivers and their families may be served efficiently and better sustained in the community through this collaborative approach.

**APPENDIX A First-Link Referral Form**



**FIRST LINK REFERRAL FORM**

Fax to: 416-322-6656

Online form available at: [www.asmt.org/firstLinkReferralFormOnline.htm](http://www.asmt.org/firstLinkReferralFormOnline.htm)

PLEASE NOTE: For use with Person with Dementia &/or Caregiver who reside in Toronto \*\*

Date: _____	
Please Contact: <input type="checkbox"/> Person with dementia <input type="checkbox"/> Caregiver/Contact	
<b>Person With Dementia:</b> Name: _____ Diagnosis: _____ Person with dementia resides: <input type="checkbox"/> Alone <input type="checkbox"/> With a caregiver <input type="checkbox"/> In a residential facility Daytime Phone #: (1): _____ (2): _____	<b>Caregiver/Contact Name:</b> Name: _____ Relationship to person with dementia: _____ Daytime Phone #: (1): _____ (2): _____ May leave a message: <input type="checkbox"/> Yes <input type="checkbox"/> No

**REFERRAL INSTRUCTIONS**

Please Contact:  As Soon As Possible  Two Weeks  One Month

**Referral Source:**  
 Name: \_\_\_\_\_  
 Organization/Agency: \_\_\_\_\_  
 Phone: \_\_\_\_\_

**Additional Information:**  
 \_\_\_\_\_  
 \_\_\_\_\_

**PATIENT/CLIENT INFORMATION**

1) On a scale of 0 to 10, how confident are you in providing care?

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10

Not at all confident                      Somewhat confident                      Extremely confident

2) On a scale of 0 to 10, how stressed do you feel regarding your caregiving role?

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10

Not at all stressed                      Somewhat stressed                      Very stressed

For more information please contact:  
 George Tony, First Link Coordinator, Alzheimer Society of Toronto; Tel.: 416-640-6310, Fax: 416-322-6656, Email: [firstlink@alzheimerstoronto.org](mailto:firstlink@alzheimerstoronto.org)  
 \*\* Toronto, City of York, East York, Etobicoke, North York, Scarborough



**FOR INTERNAL USE ONLY:**

<b>Counsellor:</b>	
<input type="checkbox"/> Explained and offered AST services <input type="checkbox"/> Information package was sent to client <input type="checkbox"/> Client prefers to contact AST, as needed <input type="checkbox"/> Counsellor was unable to reach client <input type="checkbox"/> Client was referred to local chapter <input type="checkbox"/> Counsellor will call client again (specify when) _____ <input type="checkbox"/> Counsellor will meet with client _____ <input type="checkbox"/> Other _____	<b>Contact/Attempts:</b> ___/___/___ at _____ ___/___/___ at _____ ___/___/___ at _____ <b>Comments:</b> _____ _____



APPENDIX B2 Post-Session Participant Survey

**CCAC Training**

Post Session Participant Information

Date: \_\_\_\_\_

**1. On a scale ranging from 0 to 10, how would you rate your knowledge about dementia ?**

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
Extremely Moderate Extremely High  
Low

**2. On a scale ranging from 0 to 10, how confident are you about providing services to people with dementia and their caregivers?**

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
Not at all Somewhat Extremely  
Confident Confident Confident

**3. On a scale ranging from 0 to 10, how important do you think it is for SEC Coordinators to receive dementia specific training?**

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
Not at all Somewhat Extremely  
Important Important Important

**4. Since the training began, have you changed anything about your practice?**

Yes  No

**5. If you have, how?**

**6. How helpful did you find these sessions?**

Not at all helpful  Somewhat helpful  Very helpful  Extremely helpful

**7. In your opinion, what would help you to be more confident in providing services for persons with dementia and their caregivers? (Circle all that apply)**

- a. Reinforcements (e.g., stickers, posters or key chains)
- b. More practice time in training sessions
- c. An additional training session
- d. No further assistance needed
- e. Other suggestions: \_\_\_\_\_

*Thank you for completing this evaluation form!*

APPENDIX B3 Participant Session Feedback

**CCAC Training**  
**Session Feedback**

Date: \_\_\_\_\_

1. Please rate this session by placing an "X" in the appropriate box:

	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Excellent</i>
Organization & content of the session				
Clarity of the information				
Group discussion				
Presenters' knowledge of the subject				
Session overall was:				

2. The length of the training session (        hours) was:

Too short         Just right         Too long

3. Was the session helpful to you?

Not at all helpful         Somewhat helpful         Very helpful         Extremely helpful

4. Did you feel you were given too much or too little information?

Too little         Just right         Too much

5. Did you learn something? If yes, what did you learn?

6. What did you like MOST about the training session?

7. What did you like LEAST about the training session?

8. Would you recommend this training to others?

9. Please provide your suggestions on how the training session could be improved:

*Thank you for completing this evaluation form!*

## APPENDIX C Legends for topics discussed between the AST counsellors and the caregivers.

<b>Issue</b>	<b>Details</b>
ADP	Adult Day Program
AccessAlliance	Translation Service
Alternative Housing	Moving to a new type of housing that is not a long-term care facility (i.e. retirement home).
Approaches to Care	Concerns surrounding practical issues related to caregiving but excluding discussions surrounding challenging reactive behaviours (i.e. how to communicate with PWD or finding new ways to connect). Approaches to Care focuses strictly on here and now, unlike “future planning” that focuses on the future.
AST Services	Explanation provided of AST services of a discussion is held about types of services offered
Behaviour Management	Concerns surrounding behavior and a discussion on strategies to manage challenging reactive behaviours.
CG Project	Caregiver Project. Offers caregivers with a financial need a support to fund various caregiving related necessities.
CG Stress	Caregiver Stress captures emotional aspects of caregiver’s experience and a discussion surrounding these emotions.
Counselling Request	Callers who are looking for continuing support from a counsellor one-to-one.
Education	Counsellor initiated. Unlike “approaches to care”, education provides information to Caller that is relevant but was not explicitly requested by Caller.
Finances	Concerns surrounding financial matters relating to caregiving.
FL referral process	Questions about the <i>First-Link</i> referral process
Future Planning	Concerns surrounding progression of disease, changes that may occur and what to plan for. Future planning focuses strictly on the future, unlike “approaches to care”.
Health Concerns	Concerns surrounding health issues of PWD or Caller (caregiver). Health concerns focuses on physical medical complications and how those impact care.
Home Help	Concerns around home-related issues (i.e. cleaning, cooking, lawn mowing)
LM/No Contact	Left voicemail/No contact made. Involves a message that communicates an update to an issue/invitation to call for a specific purpose. This is counted as an issue discussed.
LTC Decisions	Long-term care decisions. Concerns surrounding decisions about long-term care related issues (i.e. life in long-term care). There is no intention of placement in near future.
LTC Placement	Long-term care placement. Concerns surrounding placement issues that may come up (i.e. adjustment to life in long-term care), or an intention of placement in near future.
Other; See Notes	Other issues including attending workshop, PWD passing away, contact number not in service, or case terminated.
Package Request	Information package requested by Caller or initiated by counsellor
Physician Search	Search for a physician.
POA	Power of Attorney. Concerns surrounding implementation process or details of power of attorney.
Referred to Local Chapter	Caller not living in GTA, who was referred to a local Alzheimer Society chapter.
Respite Care	Concerns surrounding burden of care and respite care strategies/services available.
Safely Home	Discussion on the Safely Home program.
Self Care	Addressing concerns surrounding Caller’s (caregivers) physical and psychological well-being in the context of caregiving.
Support Group Request	Callers who are looking for continuing support within a group setting.
Transportation	Discussion on concerns surrounding transportation of PWD or caregiver or both.



