



**An Evaluation of Alzheimer Society of Toronto's Dementia Care  
Training Program and Behavioural Support Training Program**

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## 1.0 Background

### 1.1 Program Rationale

Presently, 500,000 Canadians are living with Alzheimer’s disease and other dementias (ADOD). In 25 years, this number will increase to 1.1 million (1). In Toronto specifically, there are approximately 42,000 people living with ADOD, and by 2031, this number is projected to reach 57,800 (2).

Complex and responsive behaviours often accompany ADOD. In 2010, the *Behavioural Supports Ontario* strategy was announced and launched by the *Ministry of Health and Long Term Care (MOHLTC)*. Its overall aim is to improve the lives of Ontarians with behaviours associated with complex and challenging mental health issues including ADOD (3). The strategy is multi-pronged, and consisted of three components:

1. System coordination and management
2. Integrated service delivery
3. Knowledgeable care team and capacity building

The *Alzheimer Society of Toronto (AST)* actively takes part in developing and implementing the third pillar, which will be reached by educating nurses, personal support workers and other health care providers in the specialized skills necessary to provide care for persons living with dementia with dignity and respect. In order to align with the objectives of *BSO*, *AST* Public Education Coordinators (PECs) developed a new program known as the Behavioural Support Training Program (BSTP) to focus in on responsive behaviours management. PECs also updated the curricula for its Dementia Care training Program (DCTP) to be more compatible with the online launch and to strengthen and create better linkages to BSTP. Together, these programs are meant to build capacity and ensure that staff members in long-term care homes, hospitals and community agencies have the skills they need to respond to residents and clients with responsive behaviours.

### 1.2 Program Description

#### *Dementia Care Training Program (DCTP)*

Dementia Care Training Program (DCTP) was developed and first disseminated by *AST* Public Education Coordinators (PECs) in 2004. It was initially known as the “Enhanced Training Program for Personal Support Workers (PSW)” and held over 9 hours for a target audience of PSWs, with little or no training in dementia care. The aim is to provide them with “the requisite knowledge, attitude, insight and strategies to meet the needs of increasingly older and more medically complex residents and clients with dementia” (4). DCTP has evolved over the years, and has since become a 12-hour program. As seen in the participants’ breakdown in Table 3.1, DCTP participants are still made up primarily of PSWs (84.4%). Major components of the DCTP include a) effective communication with persons living with dementia, b) Person-Centred Care, P.I.E.C.E.S. – a best-practice learning and development initiative that provides an approach to understanding and enhancing care for individuals with complex physical and cognitive/mental health needs and behavioural changes (5), and c) U-First! – a proven and effective approach to working with people with dementia and responsive behaviours (6). These components were delivered in proven adult-learning approaches. Detailed DCTP modules’ contents can be found in Table 1.1.

Table 1.1 Contents of DCTP modules

Module 1	Module 2	Module 3	Module 4
<b>Goals</b>			
Improve participants' knowledge base and understanding of dementia in general, as well as Alzheimer's disease and other dementias and their symptoms	Introduce participants to difficult and responsive behaviours associated with dementia and to introduce the P.I.E.C.E.S. framework as an approach to understand behaviours and the needs of persons with dementia	To highlight the importance of a team approach. New concepts, U-FIRST! and P.I.E.C.E.S. are being reinforced by case studies.	To improve participants' understanding of the importance of good communication skills when working with persons with dementia.
<b>Content</b>			
Overview of Dementia and Alzheimer's disease	In depth discussion of P.I.E.C.E.S.	Discussion of homework and video from Module 2	Discussion of homework from Module 3
Introduction to Person-Centred Care	Homework: Case study to practise PIECES and the "U" portion in the U-FIRST! model	Lecture and class discussion of "FIRST" portion of the U-FIRST! model using case study	Exercise: Draw an unknown object by following instructions given by facilitator
Aging simulation: walk-a-mile in my shoes	Evaluation	Introduction to Care Team approach	Lecture and discussion on communication strategies in connecting with persons with dementia
Introduction to U-FIRST! and the Wheel		Homework: Case study to practise P.I.E.C.E.S. and U-FIRST!	Introduction to Validation Video: Validation Therapy
Evaluation		Evaluation	Graduation Evaluation & Post-Evaluation

*Behavioural Support Training Program (BSTP)*

In 2010, the *Ministry of Health and Long Term Care (MOHLTC)* announced the *Behavioural Supports Ontario (BSO)* strategy, which aims to reinvent the system of care for seniors across Ontario, their families and caregivers (3). The focus is on supporting informal and formal caregivers in coping with and managing responsive behaviours associated with dementia. In order to align with this strategy, *AST* assumed an important role in promoting dementia education with a specific focus on responsive behaviours. As a result, the Behavioural Support Training Program (BSTP) was developed and piloted in August 2012. This 9-hour program aims at building on foundations, tools and concepts learned in DCTP and applying it in a more in-depth manner to behavioural management. Participants learn to:

- Identify possible underlying causes of responsive behaviours
- Have increased level of confidence and comfort in providing care for persons with dementia who exhibit responsive behaviours
- Obtain enhanced insight of responsive behaviours from the perspective of the person with dementia
- Develop an action plan based on U-FIRST! for addressing responsive behaviours

Detailed BSTP modules' contents may be found in Table 1.2.

Table 1.2 Contents of BSTP modules

Module 1	Module 2	Module 3
<b>Goals</b>		
Review concepts from DCTP and practice communication through role play and homework	Emphasize that both behaviours and managing behaviours are complex processes. Participants have many opportunities to discuss and to practise identifying responsive behavioural triggers using old and new tools.	Prepare participants as confident team players, contributing to action plan development for clients with responsive behaviours.
<b>Content</b>		
Review of P.I.E.C.E.S.	Discussion of homework from Module 1	Discussion of homework and video from Module 2
Person-Centred Care	Video: An excerpt from “Dementia with dignity”	Lecture and detailed discussion on Action Plan Development
Therapeutic Communication	Prioritization: Learning which behaviour to address first	Before graduation, add in Complete a case study to practice concepts learnt from modules 1 and 2 and practice developing of an action plan as a team. This is followed by a graduation.
Role Play: communication exercise	Case study to practise using prioritization, PIECES and UFIRST to manage responsive behaviours	Evaluation & Post-Evaluation
Take home exercises: Communication exercise, Person-Centered Care language and values, as well as seeing from the perspective of a person with dementia	Take home exercise: reading from the perspective of family members and family caregivers	
Evaluation	Evaluation	

## **2.0 Methods**

### **2.1 Goals of Evaluation**

The Dementia Care Training Program (DCTP) and Behavioural Support Training Program (BSTP) were evaluated between August 2012 and February 2013, using a mixed method approach. The goal of this evaluation is to:

- Understand the demographics and training needs of participants for both programs
- Understand the dementia-related or behavioural challenges and opportunities that PSWs and health professionals face in their work
- Evaluate the impact of both programs on quality of care and quality of life experienced by persons with dementia
- Evaluate the personal and professional benefits to PSWs and health professionals upon completion of either or both programs
- Collect feedback from family members of persons with dementia (PWDs) whose private caregivers were attendees of either or both programs

### **2.2 Data Collection**

Quantitative data was collected at the *AST*, and managed and analyzed by Peter Marczyk. The following data was reviewed:

- Participants' demographic information
- DCTP evaluation forms: pre-training, after each session one through four, and post-training.  
BSTP evaluations forms: pre-training, after each session one through three, and post-training.
- Participants' satisfaction

Qualitative data was collected through personal interviews with three groups of key informants:

- 1) Graduates of the DCTP and/or BSTP,
- 2) managers of agencies who referred staff to the DCTP and/or BSTP and
- 3) family caregivers whose PSWs have attended the BSTP.

Interview guides were adopted from the Hum's report (4) and modified by the evaluator for the purpose of this evaluation.

Potential interviewees (graduates and supervisors) were identified by PECs from among the graduates who had completed the pilot BSTP. Family caregivers were identified by *AST* counsellors and agencies associated with *AST*. PECs obtained preliminary agreement from these individuals to be interviewed. The evaluator then explained the evaluation in detail and obtained formal consent from the interviewees.

All interviews took place in February and March 2013. Interviews lasted 20 to 30 minutes and were conducted over the phone. Interviewees signed a consent form before their participation. Interviews were audio-recorded and transcribed. Content analysis was used to identify major themes.



### 3.0 Evaluation Results

#### 3.1 Summary of Quantitative Data

Over the course of 6 months between August and December 2012, the Public Education Coordinators (PECs) facilitated a total of 11 DCTP sessions, and simultaneously over the course of 8 months between August 2012 and February 2013, the PECs facilitated a total of 6 BSTP sessions. The DCTP sessions averaged 16.9 participants and served a total of 186, while the BSTP averaged at 13.5 participants and served a total of 81 (Box 3.1). In both training programs the majority of participants were Personal Support Workers, 84% for DCTP and 78% for BSTP (Table 3.1). Other professions included Social Workers and Social Service Workers, and nurses.

**Box 3.1 DCTP Sessions facilitated between August 2012 and December 2012 and DCTP Sessions facilitated between August 2012 and February 2013:**

Session Number	DCTP Sessions	# of Participants	BSTP Sessions	# of Participants
1	Aug. 2, 9, 16, 23	14	Aug 15, 22, 29	16
2	Aug. 20, 23, 27, 29	15	Sep.11,18, 25	16
3	Sept. 8, 15, 22, 29	13	Nov. 9, 16, 23	9
4	Oct. 4, 11, 18, 25	20	Nov. 13, 20, 27	13
5	Oct. 9, 16, 23, 30	12	Feb. 13, 20, 27	10
6	Oct. 13, 20, 27, Nov. 3	22	Feb 15 & 22 (3 Sessions condensed into 2)	17
7	Oct. 15, 22, 29, Nov. 5	14		
8	Nov. 6, 13, 20, 27	20		
9	Nov. 10, 17, 24, Dec. 1	24		
10	Nov. 26, Dec. 3, 10, 17	21		
11	Nov. 30, Dec. 7, 14, 21	11		

Total Number of Participants August – December 2012: DCTP: 186 BSTP: 81	Average Number of Participants per session: DCTP: 16.9 BSTP: 13.5
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Table 3.1 DCTP and BSTP participants' profession

Participant Type	DCTP	BSTP
PSW	157 (84.4%)	63 (77.8%)
Social Worker/Social Service Worker	29 (15.6%)	7 (8.6%)
Nurse	N/A	11 (13.6%)

### 3.1.1 Participants Demographics

Participants' demographic information was collected prior to start of the training program and is shown in Table 3.2. Similarities and differences between DCTP and BSTP participants are highlighted below:

Similarities - Select demographics were similar across DCTP and BSTP participants:

- The approximate average age difference between both groups of participants was just 5.2 years, where approximate average age for DCTP was 37.5 and for BSTP, 42.7.
- Participants in both training programs also shared a similar time length of employment in the healthcare field. 50% of DCTP participants were employed for four years or less in the field, and 31% for less than one year, whereas 40.8% of BSTP participants were employed for less than four years in the field, and 24.5% for less than one year.

Differences – There were also significant differences in the demographics between participant groups:

- In general, BSTP participants have spent longer time in Canada than DCTP participants, with fewer being new settlers and more having resided in Canada for more than ten years.
- Participants in the DCTP training program speak English as a second language.
- A higher percentage (9.5%) of DCTP participants also expressed that they received too much information.
- BSTP and DCTP participants also had significant differences in the highest completed level of education. In contrast to DCTP participants, nearly twice as many BSTP participants had an undergraduate degree. Correspondingly, in contrast to BSTP participants, over three times as many DCTP participants reached high school level education.
- In order to register for BSTP, participants have to fulfill two requirements: 1) completion of DCTP/U-First within the past three years, and 2) have experience working with individuals with dementia either through placement, employment or volunteer work. Therefore, it was found that more BSTP participants were employed at the time of the training to work with persons with dementia (PWDs) than their DCTP counterparts: 56% of participants in DCTP and 83% in BSTP currently working with PWDs.
- BSTP participants also had more self-perceived knowledge about ADOD than DCTP participants: 60.8% of DCTP participants and 98% of BSTP participants felt their level of general knowledge about dementia prior to training was good or excellent
- At the start of the respective programs, more BSTP than DCTP participants were comfortable in providing care to person(s) with dementia (20.6% of DCTP participants and 44.4% of BSTP participants).

Table 3.2 DCTP and BSTP participants' demographic information

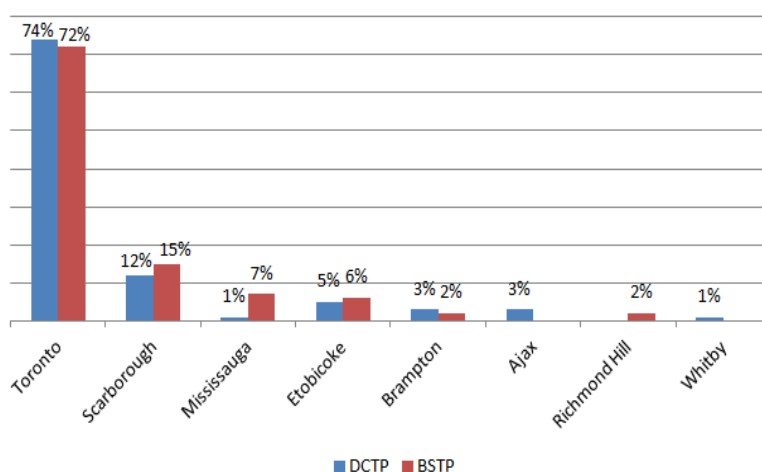
Item		DCTP	BSTP
<b>Approx. Average Age</b>		37.5	42.7
<b>Length of time living in Canada:</b>	<1 year	7%	0%
	1-4 years	40%	23%
	5-9 years	19%	11%
	>10 years	34%	66%
<b>Highest Level of Education</b>	High School	42%	14%
	College	35%	42%
	University	22%	44%
<b>English as a first language</b>		36%	51%
<b>Access to technology from home</b>		86%	96%
<b>Length of employment in healthcare</b>	<1 year	31%	24.5%
	1-4 years	50%	40.8%
	5-9 years	9.5%	10.2%
	>10 years	9.5%	24.5%

<b>Currently working with a person with dementia</b>		56%	83%
<b>Had previous training in dementia care</b>		20%	N/A
<b>Level of knowledge about AD &amp; dementia prior to training</b>	None	10.8%	0%
	Poor	28.4%	2%
	Good	55.9%	80%
	Excellent	4.9%	18%
<b>Comfort in providing care prior to training</b>	Not at all	10.3%	0%
	Comfortable	69.2%	55.6%
	Very Comfort.	20.6%	44.4%

### Which part of the city do participants come from?

Although most participants resided in the City of Toronto, the DCTP and BSTP attracted 26% and 28% of participants, respectively, from outside of Toronto including Scarborough, Mississauga, Etobicoke, Brampton, Ajax, Richmond Hill, and Whitby (Figure 3.1).

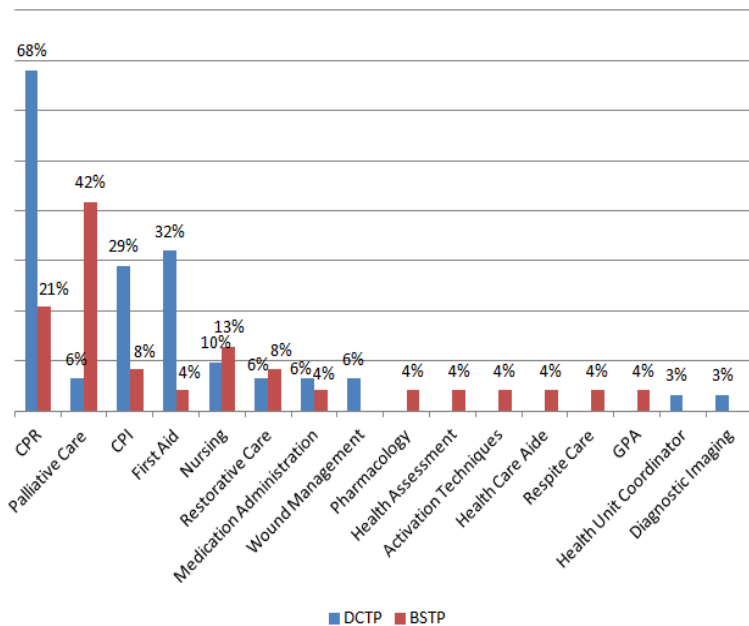
Figure 3.1 Participants' City of Residence



### What external training do participants have?

According to the data (Figure 3.2), just 20% of participants who registered for DCTP have previously obtained training in dementia. However, many DCTP participants enrolled into the program holding instrumental-type training certificates such as CPR (68%), First Aid (32%), and Nonviolent Crisis Intervention provided by *Crisis Prevention Institute* (29%). With several instrumental-type certificates but little dementia-specific training, it is clear why most DCTP participants find getting greater knowledge/understanding of dementia as the most important training need.

Figure 3.2 External training that DCTP and BSTP participants have received



### 3.1.2 Evaluation Questionnaires

#### 3.1.2.1 Response Rates

Both DCTP and BSTP were evaluated throughout the course of the training programs, by asking participants to complete evaluation surveys. DCTP evaluations consisted of pre-training, after each session one through four, and post-training. BSTP evaluations consisted of pre-training, after each session one through three, and post-training. The average total response rate from all evaluations was 71% for DCTP and 70% for BSTP (Box 2). Based on the information collected, several similarities and differences between the two training programs have been observed.

Table 3.3 Response rates for evaluation questionnaires completed by DCTP and BSTP participants

Evaluation Type:	DCTP	BSTP
Demographic Data	118 (63%)	56 (69%)
Pre-Session Evaluation	149 (80%)	N/A
Session 1 Evaluation	159 (86%)	57 (70%)
Session 2 Evaluation	141 (76%)	56 (69%)
Session 3 Evaluation	115 (62%)	57 (70%)
Session 4 Evaluation	121 (65%)	N/A
Post-Session Evaluation	123 (66%)	56 (69%)
<b>Average Total Response Rate</b>	<b>131.29 (71%)</b>	<b>56.4 (70%)</b>

#### 3.1.2.2 Positive impact of DCTP and BSTP on graduates

Upon a thorough analysis of the evaluation, it was observed that following the training program, participants in both DCTP and BSTP felt an increase in their knowledge of Alzheimer’s disease and other dementias by 35% and 29%, respectively, an increase in confidence by 29% for DCTP and 32% for BSTP. Also 91% and 100% of respondents felt that the training allowed them to provide improved quality of care to persons living with dementia by 91% and 100%, respectively (Box 3.2).

Table 3.4 Measure of change for confidence and knowledge of dementia

Change in Confidence:

Session	DCTP		BSTP	
	Mean	Mode	Mean	Mode
Pre-Session	5.5	5 (32% of part.)	6.1	6 (20% of part.)
Post-Session	8.4	8 (31% of part.)	8.9	10 (25% of part.)

Change in Knowledge of Dementia

Session	DCTP		BSTP	
	Mean	Mode	Mean	Mode
Pre-Session	4.9	5 (32% of part.)	6.3	5 (17 % of part.)
Post-Session	8.4	8 (31% of part.)	8.9	10 (26% of part.)

3.1.2.3 Self-identified training needs

The evaluation forms filled out by participants showed that although both groups of participants were able to improve the quality of care they provide, the order of importance of training needs differed between each group (Box 3.2). For DCTP participants the top three training needs, in order of importance, were greater knowledge/understanding of dementia, techniques and skills to provide better care, as well as better communication skills, while for BSTP participants the needs were better communication skills, techniques and skills to provide better care, and how to cope with responsive behaviours.

**Box 3.2 Improvement in quality of care for Persons with Dementia (PWD) and training needs of participants**

DCTP					
Improvement in Quality of Care for PWD as a Result of Training		Training Needs of Participants (self-identified)			
Yes	No	Greater knowledge/ understanding of dementia	Techniques/ skills to provide better care	Better communication skills	How to cope with responsive behaviours
91%	9%	64.4%	63.6%	55.9%	40.7%

BSTP					
Improvement in Quality of Care for PWD as a Result of Training		Training Needs of Participants (self-identified)			
Yes	No	Better communication skills	Techniques/skills to provide better care	How to cope with responsive behaviours	Greater knowledge/ understanding of dementia
100%	0%	78.6%	76.8%	73.2%	57.1%

**3.1.2.4 Satisfaction Rate over Program Delivery and Structure**

The overall program satisfaction rates for both DCTP and BSTP may be seen in Figure 3.3. Throughout their respective sessions, both DCTP and BSTP participants expressed a 99% average satisfaction rate for the organization and content of the session, clarity with which the information was provided, group discussions, audio/visual learning aides, and the presenter’s knowledge of the subject matter. However, BSTP and DCTP participants were in disagreement regarding the amount of information provided in the training sessions. For DCTP, on average 9.5% of participants felt that they received too much information, while 100% of BSTP participants felt they had received just the right amount of information in all sessions. This may be due to differences in demographics of DCTP participants – many are immigrants and may experience language barriers.

Figure 3.3 Overall Program Satisfaction Rates for DCTP and BSTP



### 3.2 Summary of Qualitative Data

As reported in the previous section, individuals with different educational and professional backgrounds attended the training program(s). Based on special requests and certain circumstances, family members of individuals with dementia may also participate. For the qualitative component of this DCTP/BSTP evaluation, a total of **16** individuals were interviewed:

#### 10 graduates of DCTP and/or BSTP

- 1 RN
- 1 OT (Clinician Leader)
- 1 Recreational coordinator
- 3 PSWs working at LTC facilities
- 3 Live-in or private caregivers
- 1 Volunteer

#### 2 Managers or agency contacts

#### 4 Family members of persons with dementia (PWD), whose private caregivers may have attended either one or both of DCTP and BSTP

Themes that emerged from these interviews include:

- Finding meaning in dementia care
- Challenges in caring for persons with dementia
  - Challenges being a PSW
  - Challenges of family members persons with living dementia (PWDs)
  - Challenges being a PWD
- Reasons for attending DCTP and/or BSTP
- Positive impact of DCTP and/or BSTP: On graduates and on PWD
- Elements of Success of the Training Programs
- Future Opportunities

#### 3.2.1 Finding meaning in dementia care

The interview data reveals a population of health professionals, specifically PSWs that are compassionate and interested in their work. They understand the challenges faced by their clients, and the importance of treating them with dignity and respect. They find meaning and satisfaction in improving the quality of care provided to their clients, and in turn, enhancing their quality of life. In some cases, this drives the desire to expand their knowledge base and that becomes the main reason for obtaining extra training.

*I very much love working with my clients. I enjoy taking care of elderly people. It's challenging but it's very much rewarding.* – PSW working at a LTC facility, attended DCTP and BSTP

*If I can make them (PWDs) smile and understand what they need, and make their day a little bit easier, it's very satisfying. A lot of them are in distress or have a hard time adjusting... they have lost a lot because of their diseases. They are in a vulnerable situation. If they have someone who can make them more at ease by providing them services, that makes me feel good.* – Recreational coordinator working at a LTC facility, attended DCTP and BSTP

*I feel obliged to my clients because I feel needed.* – Privately-hired caregiver, attended DCTP

*Clients are there not because they want to be there or they choose to be there, but they have to be there. It's our job to understand them and make them comfortable with the best possible care. – PSW working at a LTC facility, attended DCTP and BSTP*

*PSWs play a major role in their clients' lives because they are really hands-on. They take care of the physical and emotional needs, it's a holistic approach. It's a holistic way of caring. We explore their feelings and respond to the emotional needs. Our clients often times feel like they are alone and socially isolated. They have limited capacities due to their illnesses. – Manager*



### 3.2.2 Challenges in caring for persons with dementia

In carrying out their work, health professionals, PSWs, family members and clients all face different challenges. These are documented below.

#### 3.2.2.1 Challenges being a PSW

PSWs face various professional challenges. Frustrations may stem from **inexperience in managing difficult or responsive behaviours in clients**, which result in the inability to be creative, try to look for hints and explore strategies that would mitigate the situation.

*A major obstacle is when the client doesn't allow you to complete the task at hand. This happens to me with a number of Alzheimer clients. They don't want to be washed, they just wanted to be left alone. What do you do? – PSW working at a LTC facility, attended DCTP*

*My job is to make them feel comfortable, secure and safe. If I don't understand their needs, it's kind of hard to do my job. – PSW working at a LTC facility, attended DCTP and BSTP*

*Understanding their behaviours is a challenge. Certain people might exhibit certain types of behaviours and I would have to figure out what the behaviours mean, and to accommodate them accordingly. Another challenge associated with this is to ensure that people around these clients do not feel intimidated or disrupted. – Recreational Coordinator working at a LTC facility, attended DCTP and BSTP*

Another prominent theme that arose from the interview data is **barriers encountered in the work environment or culture to practice good dementia care**. For example, in a long term care facility, where staff have to adhere to a tight schedule, effective dementia care may not be a priority 1) among colleagues and 2) at the management level.

1) *When I try to tell some of my colleagues that when a certain client displays specific behaviours and that those behaviours may have a meaning, they just brushed me off.' - PSW working at a LTC facility, attended DCTP and BSTP*

2) *For my placement when I was PSW student, I worked at a new building and all residents with dementia and behaviours were organized on one floor. They were taken care of by staff who have the experience and skills to manage these conditions. That makes sense. In the home where I'm working right now, it's all over the place. Everyone, even staff with little training and knowledge, would be assigned to work with clients with dementia. That doesn't make sense. Is it bad management? Bad communication? What is it - I don't know." – PSW working at a LTC facility, attended DCTP and BSTP*

**Job isolation** is not only faced by private PSWs but also casual part-time PSWs working in big organizations. Their circumstance puts them into a disadvantage when trying to understand their clients. They have to put in more time and effort to problem solve on their own.

*There are many people working at my place, and we are all 'loosely organized'. A lot of us are casual part-timers but there are regular staff too. Of course, there are some co-workers who are more passionate about their job than others. However in general, I found that there is a little lack of communication. There is a lot of figuring out on your own which takes time from learning about my clients better. – PSW working at a retirement home, attended DCTP and BSTP*

*I want to work collaboratively with people. I want to work in a team. One of the things I find challenging is that I am on my own doing detective work a lot of times. – Private PSW, attended DCTP*

At times, the **staffing schedule** does not allow PSWs to practise person-centered care.

*Since I'm a casual part-time worker, I get a different assignment every time I go in. So, unfortunately, I don't actually have a steady client whom I can get to know better. I have to rely on the chart. I don't have much time to practice person-centered care but I try to do it when I can. – PSW working at a retirement home, attended DCTP and BSTP*

Lastly, PSWs talked about the challenges they encounter in trying to communicate with their clients due to **language barriers and different ethnic backgrounds**.

*The client and I sometimes don't speak the same language – we have a language barrier because we are from different ethnic backgrounds. I only guess their needs from their gestures. – PSW working at a LTC facility, attended DCTP and BSTP*

### 3.2.2.2 Challenges being PWD's family members

The uncertainty that surrounds the prognosis of the person with dementia generates a high level of anxiety in PWD's family members. At times, stress may stem from the obligation and desire to care for and keep the PWD at home, which is a feat in and of itself. Add to that the family dynamics and history, caring of a PWD becomes an extremely burdensome undertaking without professional support and guidance. Lastly, family members have a hard time accepting PWD's diagnosis, subsequently refuse to adapt.

*My mother got vascular dementia and she got it very suddenly. It was not a slow developing thing. I don't know what's going to happen to her down the road. She might become aggressive and we would have to manage that when and if it happens.*

*We are trying to keep her at home, that's where she wanted to stay. We will ensure that she's getting the best care, including medical care from the geriatrician and physical help at home, things that are necessary to make her comfortable. We are hoping that she'll die at home in her sleep, which is what she wants.*

*The stress I'm feeling comes from trying to work things out with my brother. For example, we are disagreeing on having an extra half day with the cleaning lady. The live-in caregiver and the cleaning lady provide a lot of emotional support for mother. My mother has lost a lot of her friends and she can talk to these people and complain about things.*

*Sometimes we would attribute certain behavioural issues to our mom's personality, since we have known our parents our whole lives. We thought our mom is being stubborn but in truth, she doesn't have the ability to comprehend and react in appropriate ways. Knowledge of the disease and what to expect is important for us.*

### 3.2.2.3 Challenges being a PWD (individual being taken care of)

The needs and challenges faced by persons with dementia cannot be overlooked. Their main issue, as discussed in the interview data, seems to be **the loss of privacy**.

*My mother used to say jokingly, "I think everyone's seen me naked now". It can be awkward to be taken care of and helped in the shower, especially when she is an independent and private woman to begin with. – Daughter whose mother lives with dementia*

*In the beginning, it felt unfamiliar. My parents are incredible private people. My father was dogmatic to the point of it will never happen. But I had no other way of having my parents live at home, so having the live-in caregiver was the only way. I had to make it work. – Daughter with both parents living with dementia*

### **3.2.3 Reasons for attending DCTP and/or BSTP**

Individuals enrolled in Alzheimer Society of Toronto's training program(s) for various reasons. They may self-register or be recommended by their employers or the PWD's family to participate in the training program(s). In some cases, participants simply would like to be better equipped.

*For me, it is personal development. I believe that this is a booming field and I would like to get as much knowledge as possible.* – PSW working at a long term care facility, attended DCTP

In many cases, participants have completed a PSW diploma program but the basic education may not be sufficient for them to care for individuals with dementia. Therefore, attending Alzheimer Society's DCTP and BSTP served as the next level of "specialized" training.

*Behavioural incidences are not being handled overly well by PSWs because they are lacking the education. Therefore, formal behavioural support training is very important for them, but they may not be aware of the opportunity available to them at the Alzheimer Society of Toronto. This needs to be publicized across the board.* – Clinician Leader at a long term care facility, attended DCTP and BCTP

*Our live-in caregiver did have an 8-months PSW training and a 2-weeks placement at a nursing home on the dementia floor. She did have some idea. But at a nursing home, the routine and the setting is different* – Family member whose live-in caregiver attended DCTP, and has enrolled in BSTP

Also, live-in or private caregiver may not be a PSW or health professional by training. Having the training from the Alzheimer Society of Toronto would allow these individuals to acquire the necessary dementia care knowledge to complement their on-the-ground experience and "intuition":

*She is a teacher by background. The extra education will really stand her in good stead. She can take her practical experience and now base it in specific training. Intuition goes only so far and she needed the background.* – Family member whose live-in caregiver attended DCTP and BSTP

### 3.2.4 Positive impact of DCTP and/or BSTP

#### On graduates

Interviewees who are graduates from the training program(s) talked about the many personal and professional “gains” through attending the program(s), which includes:

1. Expanded **knowledge** base and acquired **skills**
  - a. Knowledge of dementia and accompanying behavioural issues
  - b. Communication skills
  - c. Importance of the concept of person-centred care
  - d. Values of team-approach in caring
  - e. How to manage responsive behaviours effectively
2. Becoming **strong advocates for PWDs** and taking the initiative to **educate colleagues and family members** about better dementia care
3. Motivation to be a better professional and to **pursue higher level of education** or continuous education relating to dementia care
4. **Patience** in exploring and understanding the underlying causes of behaviours
5. Increased level of **confidence** when managing responsive behaviours and communicating with other health professionals in the care-team

Both DCTP and BSTP were able to zero in on the challenges faced by all parties involved in the care of PWDs (discussed in Section 3.2.2) and strategically guide participants in problem-solving. With better knowledge and communication skills, and armed with the different strategies and tools to manage responsive behaviours, graduates often times become more confident in providing consistent care. They also have a higher level of confidence in experimenting with the different care approaches that they have learned. Work satisfaction also increased as graduates find themselves communicating more effectively with other health professionals in the clients’ care teams and contribute to problem-solving. **These personal and professional “gains” often translate into better quality of care provided to their clients.** Interviewees’ quotes corresponding to the above “gains” are shown in *Box 3.3*.

#### On Persons with Dementia

Managers and PWD’s family members were also interviewed for this evaluation and their testimonials serve as anecdotal evidence to the successful knowledge transfer and application by program graduates in real life. Graduates are said to be “more compassionate and aware” and “instead of wanting to be a health care provider, they now want to help and to be a part of this person’s life”. These translate into improved quality of life for the clients. Their success stories are shown in *Box 3.4*.

### Box 3.3 Positive impact of DCTP and BSTP on program graduates

#### Positive impact

Expanded knowledge base and acquired skills

a. Knowledge of dementia and accompanying behavioural issues

#### Interview Quotes

*With an understanding of dementia, I now know that when they get upset it's not about me and it's not because I was providing bad care. They act and react because of the disease, so I can't take it personally. This is helpful for me psychologically, because I can now be confident and focus on providing consistent care. – Private PSW, attended DCTP*

*The job can be challenging for PSWs at times because they tend to take clients' behaviour issues personally and perceive that the clients are acting out on them. The training program(s) provided them with knowledge about the disease, which cleared things up for them. – Manager*

b. Communication skills

*I do have a few clients who have Alzheimer's and dementia. During the training program, I learned a few communication techniques to get people up using actions. For example, I tried giving the client a pat on the back before moving them up or I would show them what I was going to do so that they could mimic. That was very helpful. – Recreational coordinator working at a LTC facility, attended DCTP and BSTP*

c. Importance of practising person-centred care

*The videos gave us insights into the importance of individual approach – what works for one client may not work for another. We have to keep learning and exploring the different and diverse ways of dealing with different clients. – PSW working at a LTC facility, attended DCTP and BSTP*

*When PSWs think of a client, they don't think that s/he may be feeling certain emotions. They are inclined to think 'I need to get the ADLs done. I want to get the clients cleaned, fed and I'm done'. After the training, they really see what the person is feeling. Once you get to that point, your care becomes easier. – Manager*

*I worked with a lady from India. I tried to learn some basic words from her language. That eased the tension, and she felt more at home when I was trying to provide care – PSW working at a LTC facility, attended DCTP and BSTP*

d. Value of team-approach in caring

#### Consulting colleagues

*I value the team approach now. If a certain client isn't communicating his/her needs, I would go to other PSWs whom I trust and ask them for advice. – PSW working at a retirement home, attended DCTP and BSTP*

#### Partnership with PWDs' family members

*The live-in caregiver comes into an unfamiliar situation. We as family members, we know our mother, we know the baseline and how she's supposed to behave. So it is important for the caregiver to communicate with us, and that's what she's learned through the training. - PWD's daughter whose live-in caregiver attended DCTP*

*I really use the family involved with the clients as my first point of reference, use them as a strong partnership regarding how to approach that client, try to delve into who the client is prior to the dementia. I can then use that information to problem-solve and to make care plans. e.g. if my client likes bubble bath, I'll try that to see if that would relieve behaviors such as resistance to taking a bath. - PSW working at a LTC facility, attended DCTP and BSTP*

e. How to manage responsive behaviours

#### Setting priorities

*There are two stages to dealing with behaviours. 1) how to control it in the moment: how do I prevent the behaviours from escalating and 2) is identifying the trigger so that it won't happen again. – PSW working at a LTC facility, attended DCTP and BSTP*

#### Trying different strategies

*I take into considerations everything that I've learned from the course, so looking at the environmental set up, ruling out other underlying factors. For example, looking at their bowel routine, see if the client is experiencing constipation or any acute changes. – PSW working at a LTC facility, attended DCTP and BSTP*

*It opened my eyes to particular behavioural issues that I didn't know before. The more I learn about something, the more angles I can use to look at a certain situation. Before I may have had two angles, and after the training program, I may have five angles. – PSW working at a retirement home, attended DCTP and BSTP*

#### Experimenting and practising in real life

*Before I attended the DCTP and BSTP, whatever training I got from school was just the basics. What I learned from the training programs I can practice at my job, since the cases discussed in class are drawn from real life situations. I can apply the knowledge right away on my client and that in turn, gives me more confidence. – PSW working at a LTC facility, attended DCTP and BSTP*

### Box 3.3 (Continued)

#### **Positive impact**

Becoming strong advocates for PWDs and taking the initiative to educate colleagues and family members about better dementia care

Motivation to be a better professional and to pursue higher level of education or continuous education relating to dementia care

**Patience** in exploring and understanding the underlying causes of behaviours

Increased level of **confidence** when managing responsive behaviours and communicating with other health professionals in the care-team

#### **Interview Quotes**

*I have talked to the wife of a certain client, who was upset about how the husband was behaving "irrationally". I was able to explain to her that it's not his fault. By telling her what he's probably feeling at the moment made her more at ease. I did recommend that she attend a training program with the Alzheimer's Society. - PSW working at a retirement home, attended DCTP and BSTP*

*My live-in caregiver told me that it (training) has proven very successful with my parents. She is more confident because she understands why others behave in a certain way. If they (people she's working with) don't understand the part that she does, she is more tolerant and gives the more information. It's interesting to see how it's paid forward. - PWD's daughter whose live-in caregiver attended DCTP and BSTP*

*Care is a two-way process. While learning how to deal with a client's behaviours, I have also I have to learn how to manage my own emotions and behaviours, in order to give the utmost care to the person. - Nurse, attended DCTP and BSTP*

*My live-in caregiver is a teacher by background. She doesn't have a PSW designation. The training program has therefore inspired her to pursue a PSW designation, to understand that there is value, to feel that this is purposeful. She now feels that this is her calling. - PWD's daughter whose live-in caregiver attended DCTP and BSTP*

*I have students who go on to be medical assistants, RNs, RPNs, some have gotten jobs as PSWs at CCAC and, some have gone on to work in nursing homes. - Manager*

*I have more patience. If something doesn't work right away, I don't get frustrated with myself. I just try to find different approaches. I have a wider view of the problems now. - Nurse, attended DCTP and BSTP*

*I took away from the program the practical use of the tools, communications skills, and a greater level of confidence. I do respect the boundaries because there are other health professionals in the building. But I now feel like I have something to offer. - Private PSW, attended DCTP*

*It adds to the professional credibility because I'm using common language with physicians and whomever else I'm talking to. I build better rapport within my team. - Clinician Leader, attended DCTP and BSTP*

## **Box 3.4 Success stories: Positive impact of DCTP and BSTP on the clients (persons with dementia)**

### **Quotes**

#### **Increased level of patience, application of creativity and person-centered care**

##### **→ More comfortable and calmer routine for PWD**

*DCTP and BSTP help my live-in caregiver understand the issues that the person with dementia (PWD) is dealing with. With that understanding, she becomes more adaptive and can support PWD in an effective manner. For example, she works on a timeline but my mother doesn't necessarily have the concept of time. On the days when my mother has to go to the day program, our live-in caregiver has to get my mother up, dress her, feed her breakfast and send her to the program. It takes a lot of patience and flexible application of little tricks here and there. That level of comfort and patience comes with training, and a good understanding of my mother's likes and old habits. – Family member whose caregiver attended DCTP and BSTP*

##### **→ Calmer and more engaged PWD**

*Clients and their families are sometimes pleasantly surprised when I pull in activities based on things clients have enjoyed in the past. People are quite happy with the outcomes and the positive impact these activities may have on the clients, calming them and getting them engaged and less irritated. – Recreational Coordinator who attended DCTP and BSTP*

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#### **Better communication techniques**

##### **→ Greater sense of control in PWD**

*Regarding meal preparation, she used to ask my mother "What would you like for dinner?" My mother usually can't come up with an idea and may get frustrated. Now, after the training, she (the live-in caregiver) would have in the back of her mind a couple of things that she wants to make with my mother, and would say to her, "I'm thinking of making dinner with you, what about this or this?" My mother now feels she's got control over her meal, and she doesn't feel stupid because she couldn't pull up the idea. – Family member whose private live-in caregiver attended DCTP and enrolled in BSTP*

##### **→ Greater sense of independence in PWD**

*Our live-in caregiver has learned to give my mother "space". Mother needs to feel independent, and have a purpose in life, and be supported so that she does what she's able to do. Our live-in caregiver used to tell my mother, "ok, we are making apple crisp today". Now she would say, "I thought you would like to make some apple crisp today, is that ok with you?" That seemed to make her feel better about herself. – Family member whose private caregiver attended DCTP and BSTP*

##### **→ PWD's needs better met**

*The style of communication was a concern to us. Our live-in caregiver's personal style is very "bossy", and her communication style is too abrupt. She would say to my mother, 'You need to have a bath now'. She also lacked the general knowledge of what mother's needs are. After taking the training programs, she gained understanding of how there are brain damages related to the disease. She now realizes that she has to change since my mother can't. – Family member whose private caregiver attended DCTP*

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#### **Adaptation/Application of PIECES and UFIRST**

##### **→ Building trust and rapport with PWD**

*My father is full blown behavioural. He's very articulate. He's very ambulatory with the walker. It's a very intimidating circumstance with any behavioural manifestation. The caregiver has learned to, with confidence, read his signals. She understands when to engage and when to disengage, when to distract, and when to exit. She really attunes herself to my father's needs. She uses the tools available to her within the confines to provide the best care she can. The training therefore gives her great sense of independence and boosts her self-esteem, and my father complete trusts her. – Family member whose private caregiver attended DCTP and BSTP*

##### **→ Effective documentation within organization**

*The BSTP allows me to take a step back when confronted by responsive behaviours. I try to appreciate what the confounding variables and the behaviour triggers may be. I automatically think PIECES. That's actually what we are using at Baycrest for documentation. We have received a lot of positive feedback on using that format. – Clinical leader, attended DCTP and BSTP*

##### **→ Reduced confusion in PWD**

*There was a scenario when my mother became confused at night. My live-in caregiver was able to apply a framework (PIECES) in figuring out what was going on. In the morning, we sit and talk about why last night wasn't so good and was there something we could have done differently. It is important to get into the habit of using these tools to do detective work, instead of just rolling on with life. – Family member whose private caregiver attended DCTP and BSTP*

### **3.2.5 Elements of Success of the Training Programs**

#### 3.2.5.1 Variety of learning styles

There are certain elements in DCTP and BSTP that made the programs relevant and successful. In relation to the styles of presentation, participants particularly enjoyed the case studies, simulation and the videos. These formats are proven effective in adult learning. In depth discussion guided by the facilitators are especially beneficial for participants. Having the opportunities to participate in simulation and to practise using different approaches also makes things real and more relevant.

##### Case studies, group discussions and practices

*I prefer to bounce ideas off other people so discussions of cases work wonderfully for me. – PSW working in a LTC facility, attended DCTP*

*I found that the case studies – when we discussed in depth a specific case, and the specific behaviours that arose and how to manage those – those are very helpful. I also found it useful when the facilitator shared from a medical point of view, how people actually feel, so that I learn how to step into their shoes and accommodate them better. – PSW working in a LTC facility, attended DCTP and BSTP*

*The second training program (BSTP) exposed me to more cases and learning the different approaches to handle and manage upsets: how to change the environment or situation, to explore what underlying problems would have caused the upset. I learn to assess if these triggers are changeable. I had many opportunities to practise and discuss the different strategies and communication approaches. – PSW working in a retirement home, attended DCTP and BSTP*

##### Simulation

*I enjoyed the simulation. If you can put yourself in your clients' shoes, you appreciate their frustrations better. – Recreational coordinator working in a LTC facility, attended DCTP and BSTP*

##### Video clips

*I remember distinctly that there was a video showing a gentleman with Alzheimer's talking about the disease and what he's experienced so far. It would be really beneficial for everyone to just hear that. There are other clips shown during Dementia 101 and they all make it so much more real. – Clinician Leader, attended DCTP and BSTP*

#### 3.2.5.2 Sharing of experiences, struggles and strategies

Participants also value the opportunities to share personal experiences and listening to others' stories. The right mix of people from different professional backgrounds and all walks of life enriches the group discussions.

*It was all new to me when I joined the program, so it provided me with a forum to share with and listen to other family members: the different family issues, values and struggles; what are the needs and how do you provide care – these have all become bigger issues than the dementia itself. – PWD's family member who attended DCTP*

*The group discussions are very helpful because you get to know what situations other PSWs have encountered and the next time when that happens to you, you have some ideas of how to deal with them. – PSW working in a LTC facility, attended DCTP and BSTP*



*Listening to experience of other people who were in the room with me enriched the learning experience. The mix of professions was interesting too – you hear the different perspectives and approaches people would use to deal with a behavioural problem. You can then try these approaches out when a similar situation happens to you. – PSW working in a LTC facility, attended DCTP and BSTP*

### 3.2.5.3 Expert coaching and facilitation by Public Education Coordinators

As aforementioned, Alzheimer Society of Toronto is seen as an excellent and credible resource for dementia-related information and training, and the Public Education Coordinators are perceived as experts in the field. PECs are perceived to be experienced facilitators who are attentive to the participants' needs, and participants trust and look to PECs for advices and suggestions.

*I've always looked at AST as an education source. I have told my live-in caregivers bits and pieces along the way but when she hears it from an objective source, it's become a much more powerful message. – Family caregiver whose live-in caregiver attended DCTP and BSTP*

*People at Alzheimer Society of Toronto are extremely passionate about what they do. They are compassionate and understanding. They explain things in very simple ways so that everyone understands. They are also very knowledgeable about what they are talking about. They are also very easy to approach, very human-oriented. – PSW working in a LTC facility, attended DCTP and BSTP*

*It was an intimate setting and I get to share what I am seeing, working in the community. Also, you know you are being taught by people who specialize in dementia and are great facilitators in case study discussions. – Clinician Leader, attended DCTP and BSTP*

*The sessions were well-facilitated. The person disseminating the information had great interpersonal skills and group-work skills. She was really able to go with the needs of the participants. – Nurse at LTC facility, attended DCTP and BSTP*

### 3.2.5.4 BSTP seen as a logical continuation of DCTP

The two programs are seen as complementary of each other: DCTP participants learn that behavioural management is an important topic and BSTP provides an appropriate avenue to further discuss and practise the different approaches. BSTP also allows participants to build on their skills acquired through DCTP using advanced learning material. The formal development of an action plan also helps support their practice.

*In the first training program (DCTP), I learned the tools and the basics. Through the simulations I understand the physical challenges of getting older. The second training program (BSTP) took this further and taught me to delve deeper into the emotions and feelings of my clients, and to creatively apply those tools I learned from the first program to understand and manage behaviours. – PSW working in a LTC facility, attended DCTP and BSTP*

*We were seeing things that we thought didn't line up. So both my sister and I (note: both are daughters of PWD) took the course and we found the information very valuable. Therefore, we made sure that the live-in caregiver also gets the education. She went through the DCTP, and we just learned about the BSTP, which focuses on managing upsets. We'll enroll her in this one as soon as AST provides us with the dates. – Family member whose live-in caregiver has completed DCTP*

### 3.2.5.5 Alzheimer Society of Toronto (AST) seen as a comprehensive resource hub for dementia care

Some participants learned about certain resources at the AST during their training, and have kept themselves updated by accessing these AST services/resources. A more formal forum may be set up for follow-up or check-in discussions with graduates.

(Note: PECs launched a facebook page “ Alzheimer Toronto PSW Community” on April 17, 2013 at the PSW Forum. This will become a place for communication and discussion.)

*I have kept in touch with my BSTP facilitator a few times and I kept referring to the website for any upcoming AST seminars and events that might be of interest to me. – PSW working in a LTC facility, attended DCTP and BSTP*

*I have actually gone on to the AST library to search for materials related to dementia and behaviours. There are always new things that I didn't know so it's good to catch up. - PSW working in a retirement home, attended DCTP and BSTP*

### **3.2.6 Future Opportunities**

Interviewees made several suggestions to refine the training programs and to help the programs develop and grow within the realm of BSO strategy.

#### 3.2.6.1 Increase Duration of BSTP

In general, participants feel like the content of BSTP was extremely relevant and the discussions were valuable. More time given to the programs would allow information to be better absorbed.

*When I attended, BSTP was only 9 hours. If they could add one more day to the program, contents would have been less crammed – Clinician Leader, attended DCTP and BSTP*

*Should add another day to the second program (BSTP). It was a little crammed as facilitator went through materials really quickly. – PSW working in a LTC facility, attended DCTP and BSTP*

#### 3.2.6.2 Providing a model to follow or coaching to deal with behaviours

Behavioural management is an important issue for health professionals, PSWs and family members. Interviewees mentioned the desire to have deeper discussions and further opportunities to practise. A few interviewees specifically suggested that participants may be put into a mock situation, and be coached on how to identify triggers in behaviours and to discuss the situation.

*Personally I would prefer even more content and deeper discussion surrounding the management of behaviours. – Family caregiver who attended DCTP*

*At the sessions, there were examples and cases given and we had the opportunity to discuss them. But it's easier to read that kind of stuff or talk about it than to actually do it. It would be nice if we could try a few things out and have someone coach us through it, saying "ok that was good." Or "may be you can try this approach", you know, giving us some constructive criticism on how we are doing. – Nurse working in a LTC facility, attended DCTP and BSTP*

*From a live-in caregiver's point of view, it would be nice if I had a model to follow. I know the AST has videos and at the sessions, they showed a little clip on communication. That was helpful. If there was something more like that around behaviours... I understand they can't address all the issues that arise because it depends on the individuals and the situations, but if they could show how triggers could be identified in a mock situation that would be useful when I encounter it in real life. – PSW working in a LTC facility, attended DCTP and BSTP*

#### 3.2.6.3 Providing Support in Transitioning into Real Life/Job Situation

Even after the training, participants may find it challenging to apply some of the techniques learned during the training programs. This could be due to time constraints and/or lack of experience encountered at work. More concrete instructions and further appropriate support may be provided to better prepare participants for real life situations. Refresher courses may be beneficial in these cases as participants could review the tools and techniques learned through the programs.

*It may be useful to provide another one for discussion near the end of the program to show how much participants would have learned. That would really help transitioning into real life situations. – Clinician Leader, attended DCTP and BSTP*

*I would like to learn more about ways our dementia clients think and what responses we should give to improve the rapport, and of course in a more efficient manner because in a nursing home, you are always running out of time. – PSW working in a LTC facility, attended DCTP*

*Refresher courses would be very helpful. We forget things when we go into the field. We get stuck with the same routine tasks and may not come across difficult situations often enough. If you don't practise it, you lose it. We should all be staying on top of things because there are constantly new clients coming in. I'm depending on the U-FIRST wheel and books to refresh my memory. – PSW working in a LTC facility, attended DCTP and BSTP*

#### 3.2.6.4 Changing the requirement to get “certified”

At the moment, eligibility of obtaining the certificates is based on full attendance in all sessions, and completion of homework and assignments. End-of-course assessments/examinations may be introduced as a requisite to obtain certificates from the program(s). Another area for development may be to make DCTP and BSTP certificates as a pre-requisite for PSWs to work with persons with dementia, which would make the certificates more relevant when it comes to hiring.

*Some people collect as many certificates as possible, but when they are hired, their employer may realize that they would need to do the course over again because half of what they should have learned in the course they did not. - Manager*

*Develop this BSTP certificate as a pre-requisite to employment, then, I think it would be an asset. - Manager*

#### 3.2.6.5 Maintaining ongoing partnerships

In order to continuously and better promote the importance of behavioural support and dementia care, interviewees feel that ongoing partnerships with different agencies and educational bodies should be maintained and further developed. Collaborative teaching process should be developed so that in-services provided at agencies could complement materials taught through DCTP and BSTP, vice versa.

*I hope it (our relationship) continues because, I'll be honest, their (AST) education department is very strong, and we need that. We're always asking them if there are any new developments, new movies, or anything that we can use. We can't have the Alzheimer Society of Toronto here every day but it's a big part of our teaching because we realize that most of our students are going to end up going on to caring for seniors because there is such a high concentration of seniors here in Ontario. It's also going to increase, so we know we need to have a close working relationship with the Alzheimer Society of Toronto - Manager*

*They (newly hired PSWs) can observe (during training) the behaviour, see the type of dementia they (person's with dementia) have, and identify the behavior that we are expecting coming from that (dementia), why is the behavior occurring, what are triggers going on. They note everything down using knowledge from BSTP training on how to do ABC charting, and my follow-up, and are now doing it well on their own. - Manager*

#### 3.2.6.6 AST Education is highly recommended for family members of PWDs

Family members of PWDs were identified by interviewees as one of most important triggers to responsive behaviours because of their lack of understanding of the disease. Therefore, it is essential to provide support and education to them before they reach the crisis stage. Interviewees believed that family members may be better prepared and educated through their active involvement with AST. This would in turn avert high-stress situations.

*Family members get so worked up and by the time my team (crisis team) gets involved that I can't even fathom trying some of these suggestions that we provide. It's really hard to get through to somebody who's so high-stressed. They just want their spouse out of the house,*

*placed into LTC or some place where they don't have to deal with the care recipients anymore. The challenge therefore lies in educating family members, so that they understand the complexity of dementia. – Clinician Leader, attended DCTP and BSTP*

*People get frustrated because they don't know about the disease and behaviours that may come with it. With a better understanding of what's actually happening to their loved ones, they can deal with it better. – PSW working in a LTC facility, attended DCTP and BSTP*

*Family members, depending on their situations, may benefit from UFIRST training. I met a woman in the program who's a daughter of an individual with dementia. She wasn't a professional but she wanted to learn about what to look out for during the course of the disease. She found the course to be extremely useful because she gets to learn from the expert at AST and hear from other professionals in the group as well. – Clinician Leader, attended DCTP and BSTP*

## 4.0 Recommendations

The following recommendations are based on results obtained from the quantitative and qualitative data presented above.

- *Encourage PWDs' family members to actively engage with AST:* Family members who are in contact with AST through other services (e.g. counselling) may be encouraged to enroll in caregiver education series. Family members may also take advantage of individual counselling. During these sessions, AST Counsellors may concentrate on how to deal with the anxiety that comes with the diagnosis and on what changes to expect. Family members will also benefit from learning about managing responsive behaviours.
- *Further develop a simulation program:* In order to give participants more opportunities to practise applying the tools and strategies, participants may be put into simulated situations, and be coached by facilitators on how to effectively identify triggers in behaviours and to diffuse situations.
- *Develop a systematic problem solving framework:* This framework will better guide caregivers in managing behaviors, while recognizing that situations differ from one individual to the next. Also, through discussion of the case studies in class, potential strategies related to the framework may arise. Participants may then add to these to their bag of tricks when they encounter complex behavioural situations.
- *Changing the requirement to get "certified":* End-of-program assessments/examinations may be introduced as a requisite to obtain certificates from DCTP and BSTP. This would increase the value of the certificates and their relevance for managers and employers when they are hiring PSW(s), who are unregulated health care workers.
- *Be sensitive to language barriers and the development of an e-learning program:* For individuals whose first language is not English, and for many other participants, it may be beneficial to learn on their own time and at their own pace using online learning tools. Considering that 100% of respondents have access somewhere to technology and 86% have access in their home, online learning may be beneficial. Several components of the training program(s) may be developed into an e-learning program. For some participants, this would also eliminate a commute from as far as Whitby, Brampton or Ajax.
- *Develop new and ongoing partnerships with agencies and educational organizations:* BSTP is shown to be an extremely valuable training program by closing the education gap in behavioural management in dementia patients. It is ready for wider dissemination. This may be done by further developing and maintaining new and ongoing partnerships with different agencies. AST may get in touch with curriculum developers to incorporate DCTP and/or BSTP as part of the curriculum. Also, collaborative teaching process may be explored with health care providers such as Baycrest.
- *Continue to develop program graduates into "ambassador" of dementia care:* Graduates may be kept engaged with Alzheimer Society of Toronto through newsletter or email updates. This

may encourage them to refresh their knowledge through the different resources available at *AST*. Graduates may promote the importance of behavioural support and dementia care in their work place, by educating family members and other staff members through examples. Graduates may also be encouraged to establish referral relationship with *AST* (e.g. *First Link*) so that more PWDs and families in need may receive appropriate support.

## 5.0 Conclusions

With the prevalence of ADOD rising, the need for qualified and formal dementia care providers increases accordingly. To meet this need, education and training programs were developed by *AST* and have been delivered to PSWs, social workers, nurses and other health professionals. By way of the current evaluation, it was found that both programs, especially the Behavioural Support Training Program, are at a prime stage for expansion and scaling up.

Besides continuously updating the curricula of the programs for in-house delivery, it is also essential to maintain ongoing partnerships with community agencies, health care providers, and educational bodies to ensure that the content is relevant to the workers and students. An online education program may also be explored to extend the reach of the programs. Once trained, it is important to keep program graduates connected and engaged with *AST*, so that they are encouraged to refresh and update their skills and knowledge using the other *AST* resources. In turn, they can promote the values of behavioural support and dementia care in their professional capacity. Lastly, more PWDs' family members may be recommended for the program, especially *BSTP*. As they become well-equipped to manage PWDs' responsive behaviours, crisis situation may be averted in turn.



## 6.0 References

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