Responsive Behaviours in Dementia: Developing and Implementing the Behavioural Supports Ontario Initiative

by

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Abstract

Behavioural Supports Ontario (BSO) was developed and implemented in Ontario from 2009-2013. This thesis used case study methodology to identify the factors that led to BSO’s development and explore the factors that may have influenced its implementation. Thematic analysis of semi-structured interview and document data sources identified the factors leading to the development of the BSO initiative included: (1) an increasing awareness of the negative effects of inappropriate care; (2) the ineffective use of emergency departments; (3) high numbers of alternate level of care days; (4) uncoordinated care across care provider organizations; and (5) ongoing staffing issues related to lack of time and training on how to provide appropriate care to people with problematic (responsive) behaviours. Factors which influenced BSO implementation included the expansion of funds for the long-term care sector, a growing sense of implementation fatigue, and the loss of knowledge when BSO trained staff left their positions.
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1 Introduction

Patients who exhibit problematic behaviours while receiving health care are part of a complex and pressing issue across health and social care systems. The impact of these behaviours can include longer hospital stays, longer wait times to receive care, and poor care experiences for patients and families. These impacts are connected to a system-wide dilemma of how problematic behaviours are viewed and responded to by care providers.

Problematic behaviours are seen among people who have a mental illness (Belluardo-Crosby, 2011), who are experiencing addiction to a substance (Volavka & Swanson, 2010), or who have a neurological condition, such as Alzheimer’s disease or Parkinson’s disease (Aarsland, Zaccai & Brayne, 2005; Kalia & Lang, 2015). Problematic behaviours have been termed “responsive,” and include actions from a person that communicate discomfort with something related to the physical body (e.g., urinary tract or other infection), the social environment (e.g., boredom, invasion of space), or the physical environment (e.g., lighting, noise, busyness) (OANHSS, 2011). Responsive behaviours can also include “protective behaviour,” which is often interpreted as aggressive by family members and other care providers (e.g., spitting, hitting, throwing objects, physical and sexual advances).

With populations aging globally, an increasing number of people need assistance managing chronic and multiple conditions. Dementia is one condition that is rapidly increasing as the population ages (Alzheimer Disease International, 2014) and approximately 80% of people with dementia will exhibit responsive behaviours (Black, 2011). In Canada today, there are slightly more people over the age of 65 (16.1%) than there are people under the age of 14 (16%) (Statistics Canada, 2015). The pool of potential patients who may exhibit responsive behaviours increases as the population ages due to the increasing number of people reaching an age where dementia is more likely to occur. Age is the number one risk factor for dementia, and the World Alzheimer Report from the World Health Organization says a person’s risk of dementia doubles every five years after age 65 (WHO, 2012).
This thesis assumes that dementia is the driving force behind the increasing number of responsive behaviours seen among care recipients in acute care, long-term care, home and community care, and rehabilitation care settings. In Ontario, the Behavioural Supports Ontario (BSO) initiative was implemented from 2009 to 2013 with an aim to improve system-wide support for people with responsive behaviours by inserting non-pharmacological best practices into care provision activities while coordinating knowledge-sharing across providers in various sectors and across different regions of the health system (Gutmanis et al., 2015). How direct-service providers interpret responsive behaviours affects how people are treated while receiving care. By viewing responsive behaviours as challenging, or as difficult symptoms of a given condition, providers respond using crisis management approaches that can include prescribing medications to control responsive behaviours (Dupuis, Wiersma & Loiselle, 2012). The purpose of the BSO initiative was to change this crisis response to one that “prescribes” a non-pharmacological treatment in the form of direct care, focusing instead on identifying possible triggers of the behaviour for that person and addressing the triggers in order to reduce the responsive behaviour.

Scott Dudgeon and Patti Reed (2010) assert that the effect that responsive behaviours have on health system performance results from a lack of both established best practices and cross-sector coordination of care for this population. To complicate the matter, people exhibiting responsive behaviours must straddle a multitude of services between those considered to constitute health care (i.e., improving the physical and physiological well-being of a person) and those of social care (i.e., improving the social well-being of a person and the resiliency of a community around a person). The level of coverage for services that could be considered social care varies across existing publicly funded health care systems. Systems across jurisdictions differ in how health and social care services are funded and regulated. The policies that govern a health and social care system dictate which professionals can provide specific types of care, differentiate between which services are covered and which are not, and indicate what services will be universally funded and which will be based on a given set of eligibility criteria. The impact of this will be discussed in chapter 4.

The sectors of Ontario’s health system that were identified as targets for the BSO initiative included the acute care received in hospitals and urgent care clinics, long-term care received in residential care facilities, and home and community care received in a person’s home or in a
clinic in their community. Limited monetary and human resources, which are realities for Ontario’s health system, challenge the implementation of non-pharmacological approaches. Advocates for residents and staff of long-term care homes point out that there are not enough workers to provide the level of care required, and that in cases where responsive behaviours are present, the worker is limited by what they can do because they lack appropriate training and/or do not have the time required to implement non-pharmacological approaches to care (Ontario Council of Hospital Unions, 2014). These concerns have also been identified where individuals receive hospital care, at home or in the community. As will be discussed in section 5.3, the BSO initiative intended to address these concerns with targeted interventions and a modest amount of monetary investment from the provincial government, in an effort to redesign the system of care for people exhibiting responsive behaviours (Ontario Behavioural Support System Project Team, 2010).

1.1 Research Objective
This thesis explores the process of developing and implementing a specific policy initiative called Behavioural Supports Ontario in its effort to address the impact of responsive behaviours within Ontario's the health care system. Changing demographics and increasing awareness of dementia, as well as the impact of responsive behaviours on the health care system, appear to be the impetus for BSO. The initiative can be considered representative of transformation initiatives targeting specific populations and intervention processes in general. While a government response to the issue could potentially change the way care is provided to people exhibiting responsive behaviours in Ontario, the process of development and implementation may limit the overall effect of the initiative. Because of this, it is of interest to policy-makers and program implementers to be able to identify factors that may influence the formulation and execution of such policy initiatives.

1.2 Research Questions
Building from the research objective above, this thesis asked:

1. What factors led to the development of the Behavioural Supports Ontario initiative?

2. What factors had an impact on how the Behavioural Supports Ontario initiative was implemented?
This thesis draws on literature about dementia, responsive behaviours, and Ontario’s health system, as well as theories of policy cycles, and agenda-setting and implementation processes. The thesis hypothesizes that:

1. The Behavioural Supports Ontario initiative was developed in response to the increasing awareness of the impact of responsive behaviours on patient/staff safety and health system performance.

2. The implementation of Behavioural Supports Ontario was influenced by the structure of Ontario’s health and social care systems, by the resources available to achieve system redesign to address responsive behaviours, and by the ability of service providers to carry out implementation activities.

1.3 Outline

This thesis is divided into eight chapters (including this introductory chapter). Chapter 2 describes different forms of dementia, and how responsive behaviours and dementia are related. Chapter 3 describes the theoretical framework used to guide and interpret the findings of this thesis. Chapter 4 describes health and social care in Canada, current legislation pertaining to health and social care, and presents information on dementia care services. Chapter 5 provides information on the related policies that preceded the BSO initiative. Chapter 6 outlines the methodology used to collect and analyze the data. Chapter 7 reports the results of the qualitative thematic analysis of key informant interviews and the documents used as data sources for this thesis. Chapter 8 contains a review of the thesis, a review of the findings, a discussion of the findings as supported by the literature and theoretical framework, and identifies the limitations, contributions, implications, and conclusions of the thesis.
Chapter 2
Dementia and Responsive Behaviours

Chapter 2 presents a description of dementia, the common forms of dementia, the responsive behaviours associated with various forms of dementia, and the treatment options commonly used.

2 Dementia

Dementia is an umbrella term for a number of conditions that affect the brain. As a syndrome and not a specific disease unto itself, it encompasses a wide range of symptoms associated with a decline in memory or other thinking skills that are severe enough to reduce a person’s ability to perform everyday activities. Common symptoms include memory loss, difficulty thinking, loss of judgment and reasoning abilities, as well as changes in mood and behaviour (Holmes, 2008; Gililland, 2010).

In the vast majority of cases, dementia is non-reversible, meaning patients will experience a continual decline as time progresses and symptoms grow. Reversible dementias are usually attributed to infections caused by viruses, bacteria and fungi, or a reaction to a drug (Tripathi & Vibha, 2009). The most common types of non-reversible dementia include Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Oboudiyat et al., 2013; Rabins & Blass, 2014). Dementia is predominately a syndrome of later life, though it can begin at any age after childhood. Dementia that begins before the age of 65 is known as young-onset dementia, and affects about one person in every 1,000 people under the age of 65 in Canada (Alzheimer Society of Canada, 2015a).

There are a number of modifiable and non-modifiable risk factors that increase a person’s likelihood of developing a form of dementia. Modifiable risk factors can be altered by a person’s diet, physical and mental exercise, and other lifestyle characteristics; these factors include high blood pressure, obesity, tobacco smoking, and a sedentary lifestyle (Oboudiyat et al., 2013; Chen, Lin & Chen, 2009; Fillit et al., 2008; Azad, Al Bugami & Loy-English, 2007). Non-modifiable risk factors are defined as factors that cannot be changed by a person to reduce their risk of developing a form of dementia. These factors are related to biology or the presence of another health condition. Biological non-modifiable risk factors include age, the presence of
specific genetic markers, and familial history of dementia (Azad, Al Bugami & Loy-English, 2007). Other non-modifiable risk factors are related to the presence of conditions such as Parkinson’s disease, Huntington’s disease, multiple sclerosis, chronic kidney disease, HIV, or diabetes in mid- to late life (Oboudiyat et al., 2013; Chen, Lin & Chen, 2009; Biessels et al., 2006).

Current research indicates that a combination of population aging, poor diet, sedentary lifestyle and early diagnosis is contributing to an increasing number of people living with dementia worldwide (Reitz, Brayne & Mayeux, 2011; Barberger-Gateau et al., 2007). In 2015, Alzheimer Disease International (2015) estimated there were 46.8 million people worldwide living with dementia. Within Canada, a population health expert panel convened by the Alzheimer Society reviewed available data and estimated that today there are 564,000 Canadians living with dementia (Alzheimer Society of Canada, 2016).

2.1 Forms of Dementia

Dementia is caused by changes in the brain and leads to a decline in a person’s ability to function over time (Jablonski, 2013). Each form of dementia manifests differently and symptoms can vary greatly by person; each person’s experience of dementia is unique. It is beyond the scope of this thesis to discuss the 50+ conditions that lead to dementia. Instead, the most common forms of dementia are presented below in section 2.1, followed by a discussion of responsive behaviours associated with dementia (section 2.2), and the treatment approaches used (section 2.3).

2.1.1 Alzheimer’s Disease

Alzheimer’s disease is the most common form of dementia for people over the age of 65 and accounts for around 60% of diagnoses (Gililland, 2010). It is characterized by “plaques” of dense proteins known as beta-amyloids that become toxic to the brain, and “tangles” that interfere with vital processes and choke off living brain cells (Oboudiyat, et al., 2013). The hallmark of Alzheimer’s disease is the progressive deterioration of the brain, resulting in the continual decline of a person’s ability to perform everyday activities. As brain cells degenerate and die there is a marked reduction in the size of the brain. Identifying this shrinkage was the primary method of diagnosis post-mortem. The development of Pittsburg compound B in 2002 made diagnosis through neuroimaging possible. This compound binds to the beta-amyloid plaque and
can be detected using nuclear imaging technology (Shagam, 2009). This allows radiologists to be able to identify Alzheimer’s disease in its early stages and distinguish it from other forms of dementia.

The most significant risk factor for Alzheimer’s disease is age, and more women will develop Alzheimer’s disease than men due to their overall longevity. There are also identified genetic markers that have been linked to the development of Alzheimer’s disease. These include the Alzheimer amyloid precursor (APP) gene on chromosome 21, presenilin-1 gene on chromosome 14 and presenilin-2 gene on chromosome 1 for young-onset Alzheimer’s disease, and the apolipoprotein E epsilon 4 (APOE e4) gene version on chromosome 15 for Alzheimer’s disease with onset after age 65 (Gililland, 2010).

2.1.2 Vascular Dementia

Vascular dementia is the second most common form of dementia and is directly related to a person’s vascular health. Vascular dementia accounts for up to 20% of all cases of dementia, and usually appears suddenly in comparison to the slow progression of symptoms seen in Alzheimer’s disease (Black, 2011). This is because vascular dementia is caused when a vascular incident (such as a stroke) results in the brain being denied blood and oxygen, leading to brain cell death (Gililland, 2010).

Unlike Alzheimer’s disease, vascular dementia is preventable and progresses only when additional vascular incidences occur that further limit the supply of oxygen to the brain. Because of this, risk factors for developing vascular dementia are essentially the same as those for heart disease and stroke. This includes the presence of hypertension, diabetes, and family history of poor vascular health, as well as factors that increase a person’s risk of hypertension, such as smoking, obesity, and physical inactivity. Men and people of African descent are at a higher risk for vascular dementia because of a higher risk of severe hypertension (Gililland, 2010; Black, 2011).

2.1.3 Other Causes of Dementia

Other types of dementia include Lewy body dementia, frontotemporal dementia, Creutzfeldt-Jakob disease, and dementia as part of the progression of other conditions, such as HIV/AIDS, Parkinson’s disease, Huntington’s disease and multiple sclerosis. Lewy body dementia is the
second most common progressive form of dementia after Alzheimer’s disease and it develops more rapidly than dementia associated with Alzheimer’s. Not to be confused with vascular dementia, which is not progressive in the same sense, Lewy body dementia is caused by the presence of abnormal brain cells called Lewy bodies, which are responsible for the onset and advancement of symptoms. In order to meet diagnostic criteria, a person must have at least two of the following symptoms: shaking, rigidity, and balance abnormalities as seen in Parkinson’s disease; vacillating attention and concentration; and persistent visual hallucinations (Jablonski, 2013). Parkinson’s disease dementia is similar in that it is dementia with Lewy bodies – however, these occur after the development of Parkinson’s disease; in order to be classified as having Parkinson’s disease dementia, a person requires a prior diagnosis of Parkinson’s for at least one year (Zanni & Wick, 2007).

Originally called Pick’s disease, frontotemporal dementia is caused by atrophy of the frontal and anterior parts of the temporal lobes of the brain (Gililland, 2010). Frontotemporal dementia is thought to occur when the genes that code for certain proteins are altered, resulting in atrophy. The frontal and temporal lobes are responsible for speech, personality, and inhibition of inappropriate behaviour (Jablonski, 2013). Because of this, personality changes are usually the first symptoms to occur.

Creutzfeldt-Jakob disease is a form of dementia that is caused by an infection, though the cause of the infection is not always known. This disease causes holes in the brain, giving it a sponge-like appearance. This infection is always fatal, with 90% of patients with Creutzfeldt-Jakob disease dying within one year of diagnosis (Gililland, 2010).

A person can live with a form of dementia for many years, and can also have more than one form of dementia at the same time. This is known as mixed-dementia diagnosis (Jablonski, 2013). The length of time a person will live with dementia varies depending on the disease group. For example, people with Alzheimer’s disease live an average of ten years with a diagnosis (Alzheimer Society of Canada, 2015b), those with frontotemporal disease live an average of eight years after diagnosis, and people with Creutzfeldt-Jakob disease live, on average, less than a year with a diagnosis (Centers for Disease Control, 2014; Gililland, 2010). Providing high quality care and support to people with dementia and their families is therefore a challenge due to the variability of this syndrome.
2.2 Responsive Behaviours Associated with Dementia

As part of the progression of symptoms, 80-90% of people with dementia will experience behavioural and psychological symptoms that range from clinically mild (depression, anxiety, irritability, and apathy) to clinically severe (agitation, aggression, uncharacteristic vocalizations, hallucinations, and disinhibition) (Nowrangi, Lyketsos & Rosenberg, 2015; Black, 2011). In this thesis, the term responsive behaviours refers to actions from a person that include resisting care, aggression, and wandering. As noted in the introduction, a person may use responsive behaviours to communicate discomfort with something related to the physical body (e.g., urinary tract or other infection), the social environment (e.g., boredom, invasion of space), or the physical environment (e.g., lighting, noise, busyness) (OANHSS, 2011). Responsive behaviours can also include “protective behaviour” (e.g., spitting, hitting, throwing objects, physical and sexual advances), which is often interpreted as aggressive by family and other people providing care.

Responsive behaviours that change over the course of the disease are a source of distress for the person with dementia, as well as for their family, friends, and care providers (Dupuis, Wiersma & Loiselle 2012; Shin et al., 2005); these changes in functioning are often considered problematic or inappropriate in nature. Inappropriate behaviour that includes sexual advances or aggressive actions often generates concern and anxiety among family members and direct-service providers.

Some responsive behaviours exist as a direct result of the dementia. As explained above, the deterioration of temporal and frontal lobes seen in frontotemporal dementia reduces a person’s impulse control and social awareness of what’s appropriate and what is not (Jablonski, 2013). This is directly due to the progression of the dementia, and can result in the person with frontotemporal dementia becoming involved in the criminal justice system (Jablonski, 2013). A condition called hyperorality is a unique feature of frontotemporal dementia. Hyperorality occurs when an individual places inappropriate objects in their mouth and/or exhibits excessive eating of food. This behaviour can present special challenges in residential or hospital-based care, where the older adult attempts to eat any unmonitored food or swallows small objects they find. Additionally, individuals with frontotemporal dementia may exhibit muscle weakness, muscle atrophy, muscle rigidity, and tremors (Jablonski, 2013). The quality of life for both the person with dementia and the caregiver decreases with the presence of dementia-caused agitation,
aggression, disinhibition, anxiety, and depression (Shin et al., 2005). Shin et al's findings suggest that treatment of behavioural and psychological symptoms of dementia contributes to an improved quality of life for the person with dementia and their caregiver(s) (Shin et al., 2005). As will be discussed in section 2.3, the approach to how these behavioural and psychological symptoms of dementia are treated is associated with different health outcomes.

While some responsive behaviours can be attributed to the type of dementia and its progression, Dupuis, Weirsma and Loiselle (2012) argue that a significant proportion of behaviours should be approached with the understanding that they are responsive to various elements in the life of a person with dementia. Many behaviours can thus be considered responsive – they are not meaningless actions, but a way for the person with dementia to respond to experiences when other forms of communication are limited or constrained in some way. The authors argue that the ultimate goal for caregivers should be to discern the reason for the behaviour and respond to that instead of pathologizing the behaviour. However, these responsive behaviours can often be difficult to handle for those providing support and direct care for persons living with dementia since they require a specialized approach that views responsive behaviours in a way that counters medical norms.

2.3 Dementia Care

Dementia is a complex condition that requires varied approaches to care and support as symptoms increase over time. People with dementia typically begin their dementia journey when symptoms like memory loss or confusion appear. Some individuals choose to wait before seeking a diagnosis, while others find that receiving a diagnosis earlier gives them more time to seek treatment and support. There is no cure for dementia, nor is there any medication currently available that has been shown to delay disease progression (Traynor, 2015; Tabaton et al., 2010). Instead, typical treatment plans focus on reducing the impact of symptoms with medications and health and social care services, like those available in the home and community care or long-term care sectors. Once a person stops medication, symptoms return based on their current stage of dementia. Pharmacological treatments that are available to treat the cognitive symptoms of Alzheimer’s disease include cholinesterase inhibitors for early to intermediate stages, and memantine for intermediate to late stages (Traynor, 2015; Tabaton et al., 2010).
There are five main stages that occur in the progression of dementia, and they exist along a continuum: diagnosis, early stage, intermediate stage, late stage, and end-of-life stage (Moïse, Schwarzinger & Um, 2004). A person with this condition will at some point experience each stage of dementia, but the timing and severity of symptoms will be experienced differently from person to person and between types of dementia. These stages are not steps, but rather a way to categorize a person’s experience along a continuum. At each stage along the trajectory of dementia, some level of health and social care is typically needed.

First is the diagnosis stage. Dementia is a difficult syndrome to detect and diagnose. As with any syndrome, an earlier diagnosis means sooner treatment and the implementation of management techniques. A person can receive a diagnosis of dementia at any time, resulting in people entering the care system at different stages along the dementia continuum. During the diagnosis stage, a person will go through a number of assessments and diagnostic tests; a diagnosis is reached by eliminating other possible causes of the symptoms present (Sheehan, 2012). This stage typically begins when a person visits their primary care provider to seek answers for their symptoms; elements of this stage include recognizing symptoms, and undergoing tests and assessments. The person may receive a definitive diagnosis, a probable diagnosis or no diagnosis, which can influence their ability to access support. Assuming someone receives a diagnosis in the early stages of dementia, the ideal mix of services required to support an individual in this stage includes access to information about the syndrome, counselling support, caregiver support, and drug treatment to minimize the impact of symptoms as they develop (Alzheimer Society of Canada, 2015b).

Second is the early stage of dementia, where symptoms have a fairly minimal impact on most activities of daily life (Moïse, Schwarzinger & Um, 2004). This stage is characterized by mild symptoms that include the inability to concentrate, memory and word-finding difficulties, and mistakes in judgment. Although these symptoms may not significantly affect one’s daily life, frustration and worry are common because the person is aware of the symptoms they are experiencing. Continued information provision, counselling support, and caregiver support typically remain primary areas of dementia care in this stage. Standard courses of treatment also add medication to manage progressive symptoms of dementia through to the later stages of dementia (Traynor, 2015; Alzheimer Society of Canada, 2015b).
The third, intermediate stage of dementia is characterized by increased symptoms of memory loss, mood changes, speech difficulties, disorientation, and wandering. As a person progresses into the intermediate stage of dementia, there will be an increasing dependence on assistance from others. The risk of caregiver burnout increases because there is more reliance on the caregiver to coordinate care and to support the person with dementia. Dementia care in the intermediate stages can include partial support with activities of daily living (ADL), including eating, bathing, dressing, toileting, transferring/walking and continence, and support with instrumental activities of daily living (IADL) – tasks that are necessary for an independent lifestyle, like shopping, driving or managing finances (RNAO, 2003; Gililland, 2010).

A person reaches the fourth, late stage along the dementia continuum when they are unable to look after themselves without continuous assistance from others. This stage is characterized by severely compromised abilities due to dementia. Verbal communication may decrease and become non-existent. There is an increased likelihood of responsive behaviours, which has been shown to increase stress on paid and unpaid caregivers (Coen et al., 1997; Gitlin et al., 2010). The person with dementia requires full support with ADLs and IADLs (Moïse, Schwarzinger & Um, 2004). In addition, there is an increasing focus on services that control or manage distressing symptoms like aggression, resisting care, wandering, and other behaviour (Patel & Hope, 1993; Moss, 2011). The person with late stage dementia is frequently (but not always) institutionalized in a residential facility.

Fifth is the end-of-life stage of the dementia continuum. This stage is characterized by continuous decline, leading to an inability to speak, swallow or ambulate; palliative care becomes necessary. This involves helping the person with dementia achieve the best possible quality of life up until death by controlling distressing symptoms and pain with medical treatment, and carrying out non-medical interventions to reduce anxiety, stress, and fear (Moss, 2011). The person with this stage of dementia is frequently (but not always) institutionalized in a residential facility.

A person with dementia may or may not need dementia-specific services until later in the disease progression. Monitoring generally begins within a primary care setting, and involves assessment, diagnosis, and pharmacological treatments to assist with managing symptoms. Between the
diagnosis and end-of-life stages there is a lot of variation in terms of what services are needed, how they are accessed, and who pays for these services.

2.3.1 Treatment Approaches Used

Antipsychotic medications are usually used to treat people with mental health conditions such as schizophrenia. In addition to standard pharmacological therapies involving cholinesterase inhibitors and memantine, antipsychotic medications are also commonly prescribed to treat the behavioural and psychological symptoms seen in dementia. These medications have a tranquilizing effect on the person, and reduce the intensity of psychotic symptoms, such as delusions and hallucinations (Alzheimer’s Society, 2012). When a responsive behaviour is seen as a symptom of dementia, the use of antipsychotic medication is a common course of treatment in order to sedate the person and reduces the behaviour.

Despite not being diagnosed with psychosis, older adults who have dementia and live in residential care are often prescribed antipsychotics (Rochon et al., 2007; Jackson et al., 2012). This is concerning because the medications used to control behavioural and psychological symptoms of dementia can cause adverse reactions and are only intended for use in severe cases for less than 12 weeks (Huybrechts et al., 2012). Commonly used medications are known as atypical antipsychotics and include risperidone, olanzapine, and quetiapine (National Institute of Mental Health, 2006; Huybrechts et al., 2012; Traynor, 2015). Large-scale meta-analyses consistently demonstrate a 1.5- to 1.7-fold increase in mortality when these atypical antipsychotic medications are used (Trifirò, Spina & Gambassi, 2009; Schneider, Dagerman & Insel, 2005). Other adverse effects include cardiovascular and metabolic disturbances, extrapyramidal motor symptoms (continuous spasms and muscle contractions, motor restlessness, irregular jerky movements, rigidity and tremor), cognitive decline, infections, and falls (Nowrangi, Lyketsos & Rosenberg, 2015).

The extensive Clinical Antipsychotic Trials of Intervention Effectiveness for Alzheimer’s disease (2006) showed non-significant treatment effects of three antipsychotics (olanzapine, quetiapine, and risperidone) when compared with a placebo, meaning that there was not a significant benefit to using these medications for people with dementia. The results of these studies provide evidence of the risk of using these drugs with older patients, and reinforce the concept that they should not be used in the absence of clear need among people aged 65 and
older. Before antipsychotic medication is considered, a person with dementia who develops behavioural and psychological symptoms should be offered an assessment by their care provider to establish whether there are any underlying factors that may have triggered or may be aggravating the person’s symptoms (Alzheimer’s Society, 2012; Nowrangi, Lyketsos & Rosenberg, 2015). Recognizing and treating pain, for example, can reduce responsive behaviours significantly (Pieper et al., 2013). Pharmacological interventions to manage responsive behaviours are intended to be a last resort, after attempting all other intervention methods (Rochon et al., 2007; Nowrangi, Lyketsos & Rosenberg, 2015), but often these medications are prescribed prior to trying alternative strategies (Weeks, 2015).

There are effective ways to manage responsive behaviours through non-pharmacological treatments. These treatments can include reminiscence, social interaction, music, exercise, and other forms of stimulation, which can significantly reduce agitation and aggression in people with dementia (Gitlan et. al., 2010; Brodaty & Arasaratnam, 2012). Other ways to manage responsive behaviours use an approach to care that requires a provider to try to work with the behaviour in some way. There are four training programs commonly used in Canada that assist workers in learning the skills needed to effectively respond to behavioural and psychological symptoms in dementia. P.I.E.C.E.S™ Canada offers a 16-hour training program for regulated health professionals in the province of Ontario called “Putting the P.I.E.C.E.S™ Together” (P.I.E.C.E.S., 2015; McAiney et. al., 2007). Using the P.I.E.C.E.S™ model, professionals learn to remain mindful of the whole person in their care by assessing the person’s current physical state, intellectual state, emotional state, their capabilities, their environment, and their social and cultural needs. The Alzheimer Society of Ontario has worked with P.I.E.C.E.S™ Canada to develop a stand-alone training program called U-First! for non-regulated health professional caregivers, such as personal support workers and home health aides (Alzheimer Society of Ontario, 2015). The Gentle Persuasive Approach (GPA) is a method providers can use when there is a need to de-escalate responsive behaviours that are more severe. The seven-hour educational program focuses on respecting the person with dementia as an individual, understanding the disease process, and using supportive care strategies that are compassionate and effective (Alzheimer Society of Oxford County, 2015). Finally, the Montessori method used for teaching children has been adapted for use by caregivers of people with dementia. This method focuses on engaging the senses through physical activities and art or music therapy in
order to help the person with dementia rediscover the world around them (Huntsman, 2014). It is common for workers to combine the skills they learn through these four training programs to determine how best to effectively care for a person who is exhibiting responsive behaviours.

2.3.2 Dementia Care Best Practices

Best practices in dementia care are based on a person-centred philosophy (RNAO, 2003; Alzheimer Society of Canada, 2011). The Alzheimer Society of Canada states: “Person-centred care is a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their [social and physical] environment” (2011, p. 10). This holistic philosophy takes into account the specific needs of each person across the continuum of care, where “services and supports are designed and delivered in a way that is integrated, collaborative, mutually respectful of all persons involved, including the person with dementia, family members, caregivers and staff” (Alzheimer Society of Canada, 2011). The ultimate goal of this philosophy is to create partnership among all involved, including the person with dementia.

Some organizations that represent medical professionals have recognized the pressure that dementia places on the delivery of care, and have developed guidelines for their members on best practices in providing care to people with dementia. Many of these guidelines for medical professionals, such as those for physicians in Canada and registered nurses in Ontario, recommend person-centred or individualized approaches to care that recognize a person’s current retained abilities and limitations (Alzheimer Society of Canada, 2011; Rivard & Puxty, 2009; RNAO, 2003).

As explained in the previous section, staff that provide direct care to people with dementia can learn how to effectively anticipate and/or respond to responsive behaviours if provided with adequate training time and resources (BC Ministry of Health, 2012; RNAO, 2006; Rivard & Puxty, 2009). By using approaches such as P.I.E.C.E.S, U-First!, Montessori, and the GPA, staff can more effectively identify and respond to a person’s needs, and in doing so, better manage responsive behaviours (Gitlan et. al., 2010; Brodaty & Arasaratnam, 2012).
Chapter 3
Theoretical Framework

Chapter 3 outlines the theoretical framework used to guide this thesis, including the theories and concepts that were combined to develop the framework.

3 Theoretical Framework

The framework for this thesis is based on theories and concepts related to policy development and policy implementation. Specifically, the policy cycle framework presented by Howlett, Ramesh and Perl (2009), Deborah Stone’s (1989) theory of causal stories in agenda setting, and Sabatier and Mazmanian’s (1980) policy implementation conceptual framework have each provided a basis through which to investigate the development and implementation of the BSO initiative. From these perspectives, policy-making can be considered a cycle of problem-solving attempts, with repeated problem identification, analysis, and experimentation with potential solutions. These three theories are complementary in nature and are described in the following sections. Combining these theories forms the basis for analyzing the factors that led to the development of the BSO initiative, and what factors had an impact on how it was implemented.

3.1 Policy Cycle Framework

The policy-making process can be simplified by using a framework that breaks down the different stages of policy-making. The policy cycle involves five stages: agenda setting, policy formulation, decision-making, policy implementation and policy evaluation. As Howlett, Ramesh and Perl (2009) explain, the stages of the policy cycle follow the logic that problems are identified, solutions are identified, and decisions are made on the course of action to be taken to respond to the problem being identified. A process of implementing the “solution” to the problem follows, as well as evaluating whether the solution addressed the problem sufficiently. Howlett, Ramesh and Perl (2009) define each stage of the policy cycle framework:

In this model, *agenda-setting* refers to the process by which problems come to the attention of governments; *policy formulation* refers to how policy options are formulated within government; *decision-making* is the process by which governments adopt a particular course of action or non-action; *policy implementation* relates to how governments put policies into effect; and *policy evaluation* refers to the processes by which the results of policies are monitored.
by both state and societal actors, the outcome of which may be reconceptualization of policy problems and solutions (2009, p. 12).

This framework separates out the stages of policy-making to a degree that further considers the actors involved in each stage of the process. There is often a range of interested actors included in identifying problems with government policy and demanding government action. The process of developing solutions to the identified problems in the policy formulation stage involves fewer actors; Howlett, Ramesh and Perl (2009) refer to these actors as the policy subsystem. This subsystem includes only those actors who would have direct involvement in discussing and identifying options for government action because of their knowledge within the problem area or because they have a stake in any potential outcome. After options have been identified to change the government’s course of action, the actors involved in selecting a certain course of action are typically government decision-makers – those who have the authority to select a course of action. The process of implementing the action to be taken involves more actors than the previous decision-making stage, and even more actors are involved in the evaluation stage.

This framework is useful for understanding the basic steps involved in developing and implementing the BSO initiative; however, it also presents the policy-making process in a way that can be misinterpreted to suggest that policy-makers and relevant actors follow a linear, systematic progression through the stages. The reality, of course, is not so simple – the actual process is quite idiosyncratic, and so the policy cycle framework is more of an explanation of a process rather than a prescription for how to create public policies (Howlett, Ramesh & Perl, 2009). Theories on agenda setting and the process of policy implementation are used in this thesis and explained in the following two sections.

3.2 Causal Stories in Agenda Setting

As mentioned, within the policy cycle framework the “agenda setting” stage describes the process by which an issue comes to the attention of government. Deborah Stone (1989) identified that within the three dominant strands of agenda-setting literature, there was a focus on how media, decision makers, and other actors influence what is considered salient on the public agenda, but that there was a gap in knowledge around how situations come to be defined as problematic. Her theory of causal stories builds on the large body of knowledge related to how issues get on the public agenda. Her basic premise is that situations are only identified as
problematic if they are seen to be amenable to human action or intervention. She argues that the act of defining a political problem often rests on a causal story that attributes the problem to human behaviour rather than to accident, fate or nature. This causal story can involve an event or situation that acts as a trigger for action, or at least a trigger to contemplate action in response to the issue. The actors involved in problem definition can create a causal story that will lead to the identification of possible solutions: since causal stories seek to explain a problem, the actors involved use these stories to identify a cause and propose a solution to the problem that is based on augmentable human behaviour.

The use of causal stories in this thesis provides a way to understand what led to the development of the BSO initiative – specifically, to examine the process of problem identification that required action in the case of the BSO. This thesis expects that the identification of a causal story in the case of the BSO initiative will correspond with the government’s decision to endorse and provide resources for implementation.

3.3 Policy Implementation Conceptual Framework

This thesis draws on the public policy implementation process as presented by Sabatier and Mazmanian (1980) to assist with identifying important factors that affected the implementation of the BSO initiative. By examining literature that details case-specific experiences, their conceptual framework takes micro-level findings about implementation from cases across sectors and industries in order to develop macro-level variables for broader application. Examining traditional regulatory policies and rooted in policy implementation theory, Sabatier and Mazmanian’s framework for analyzing the process of public policy implementation stipulates the variables involved that affect the achievement of policy objectives; furthermore, it serves as a guide to analyze the process of implementing public policies in complex systems as a response to complex problems.

The application of Sabatier and Mazmanian’s conceptual framework relies on two independent factors: that the basis of the policy rests on a valid causal theory, and that the institutional structure of the jurisdiction implementing the policy has the conditions present to facilitate implementation. From their definition, a causal theory exists when, “given a stipulated objective and the assignment of certain rights and responsibilities to various implementing institutions, the target groups will behave in the prescribed fashion and the objective will be attained” (p. 545).
In order to analyze BSO using Sabatier and Mazmanian’s conceptual framework, this research must understand the causal theory underpinning this policy work as well as the institutional structure of Ontario’s health system and the subsections of the health system that care for people who exhibit responsive behaviours.

If implementation is the carrying out of a policy decision, the policy should identify the problem to be addressed and the goals to be achieved, and should focus the implementation process on reaching the identified goals.

In their view, the role of implementation analysis is to identify the factors that will achieve the stated policy goals. Their framework outlines variables that influence the process of policy implementation: (1) the tractability of the problem addressed by the policy; (2) the ability of the policy to favourably structure the implementation process; and (3) the net effect on the support for policy objectives of various political actors, including public support, support from sovereigns (in this case, regulated health professionals), and a commitment to implementation that involves skilled leadership (Sabatier & Mazmanian, 1980).

3.3.1 Tractability of the Problem Being Addressed

The first variable involves assessing whether the problem to be resolved through policy can be managed or controlled through behaviour change – the problem’s tractability. Some health problems are easier to address through policy than others, and health and social problems like the ones seen in providing care to people with responsive behaviours require a more nuanced and complex response. This can prove difficult for the implementation of initiatives to improve care for this subpopulation.

This category identifies the favourable conditions that would facilitate the implementation of government policies, such as having a clear understanding of the behavioural changes necessary to achieve policy objectives, the behaviour to be changed is not varied and involves a small subset of a given population, and the amount of behavioural change required among the target group is modest (Sabatier & Mazmanian, 1980, p. 541).
3.3.2 A Favourably Structured Implementation Process

In addition to identifying the problem to be addressed and the objectives to be pursued, the policy should guide implementation in a way that favours the successful achievement of the objectives identified – thus, the need for a structure to guide the implementation process. This implementation process should: select implementing institutions; provide legal and financial resources to the selected institutions; assign specific agencies and/or officials who are committed to achieving policy objectives to be responsible for implementation; and create opportunities for non-specified agencies/officials to participate in the implementation process.

Sabatier and Mazmanian (1980) assert that by having a clear set of consistent objectives, incorporating sound theory relating behavioural change to the objectives, and by structuring the implementation process in a way conducive to the behavioural change being sought, decision makers can increase the likelihood of achieving policy objectives. The authors claim this is the case even when seeking substantial behavioural change in the target group.

3.3.3 Non-Statutory Variables Affecting Implementation

The third element includes variables that are not explicitly written or recorded in a policy. Known as non-statutory variables, these include: socio-economic conditions and the technology available at the time; the attention paid to the problem by the media; public support for policy intervention; the attitudes and resources among constituency groups on either side of the issue; support from non-governmental organizations; and the commitment and leadership skills of those identified as implementing officials.

These variables affect the extent to which implementing agencies are able to meet expected policy outputs, the extent to which the target group for behaviour change complies with the decisions being made, and the overall achievement of the policy objectives.

As outlined above, Sabatier and Mazmanian (1980) provide a conceptual framework for understanding the variables that can have an impact on policy implementation in general. Including this conceptual framework in the theoretical framework of this thesis allows for analysis of the specific factors that influenced the implementation of the BSO initiative.
3.4 Theoretical Framework Summary

The theoretical framework used in this thesis expands on the ways in which causal stories can precede the agenda-setting stage of the policy cycle, combines the stages of the policy cycle framework, and adds depth to understanding the policy implementation stage through the grouping of factors that facilitate the implementation process. Having a theoretical framework provides a broad base for understanding the policy development and implementation process, but specific questions remain: what factors led to the development of the BSO initiative in particular, and what factors may have had an impact on the process of implementing it?
Chapter 4
Health and Social Care in Canada

Chapter 4 presents an overview of health and social care in Canada, including the legislation that governs the provision of health and social care, as well as dementia care services in Ontario. The information presented provides context for related legislation that dictates what services must be delivered, what may be provided, and who pays for the services supplied.

4 Health and Social Care Services

Health care and social care differ from one another in that health care is primarily focused on the physical and physiological well-being of a person, while social care is a combination of services that aim to improve the social well-being of a person and improve the resilience of a community (Watt et al., 1999).

There are many types of services that could be considered health care and social care, and different jurisdictions fund social care services differently than they do health care services. Health care services across jurisdictions commonly involve the provision of care to maintain or improve a person’s physiological and/or psychological health through the diagnosis, treatment and prevention of disease, illness, injury or impairment; social care services (also known as social services) across jurisdictions commonly include social work services, social support, and the promotion of social inclusion in a community (Watt et al., 1999).

Examples of health care services related to dementia include assessments, diagnosis, pharmacological therapies, symptom monitoring, and other medical services related to health conditions a person may have concurrently. Examples of social care services in relation to dementia can include access to mental health services, affordable housing, or financial supports for a disability; protection of a person from financial, physical or emotional abuse; social interaction activities; and connection to the community through initiatives like dementia-friendly groups, which aim to maintain the inclusion of people with dementia in the broader community through awareness.

Health care provision across many jurisdictional health care systems can be divided into several subsectors; the sectors directly related to dementia and responsive behaviours include primary
care, acute care, tertiary care, rehabilitation, long-term care, home and community care, and pharmaceutical care.

*Primary care* is typically situated as the “entry point” to the health care system and is provided mostly by physicians. In a growing number of cases, though, other regulated health professionals, such as nurse practitioners, are delivering primary care services (Glazier, Zagorski & Raynor, 2012). Primary care providers assess patients and provide guidance on a course of treatment, including prescribing medications and providing referrals to specialists (Health Quality Ontario, 2015a).

*Acute care* is short-term treatment for an urgent medical condition, such as an injury or illness, or recovery from surgery. If a person is not attending a hospital for a planned procedure, access to acute care is generally through an emergency department within a hospital, or an urgent care centre (Canadian Institute for Health Information, 2015a). Sometimes people with dementia are admitted to hospital through the emergency room because of an acute care need, but if responsive behaviours are present there may be a delay in hospital discharge to another level of care (Costa & Hirdes, 2010).

*Tertiary care* is consultative care which provides specialized care services to support specific health needs. This type of care is often provided in a specialized hospital or care centre and is usually accessed through referral from primary care (or secondary care as needed) (Johns Hopkins Medicine, 2016).

*Rehabilitation care* is short- to long-term treatment for a medical problem that has the potential for some level of restoration and aims to enhance functional ability and quality of life for those with physical impairments or disabilities (Ontario Hospital Association, 2006).

*Long-term care* is institutionally based care that is provided when a person’s needs exceed a level that can be managed in another setting (Ontario Ministry of Health and Long-Term Care, 2015b). This type of service is typically geared toward people who cannot care for themselves for long periods of time. It combines health and social care within a residential setting that assists a person with ADLs and IADLs (Ontario Ministry of Health and Long-Term Care, 2015b). The institutions that provide this type of care are commonly referred to as “nursing homes.” In Ontario, they are referred to as long-term care homes.
Home and community care involves the provision of health and social care services within a person’s home or in a community setting (Canadian Healthcare Association, 2009). This can be done on a short- to long-term basis. This type of care provision allows patients to remain in their homes when they are recovering from an illness or incident, or as they age and their needs result in increased dependence on others for day-to-day living (Canadian Healthcare Association, 2009).

Pharmaceutical care is drug therapy provided on a short- to long-term basis with the goal of achieving definite outcomes that improve a patient’s quality of life, including the cure of disease, elimination or reduction of the patient’s symptoms, arresting or slowing of a disease process, or for the prevention of disease or symptoms (Hepler & Strand, 1989).

4.1 Health and Social Care in Ontario

This thesis is focused on an Ontario initiative, but in order to understand the influences upon policy development and implementation in Ontario, it is necessary to provide a brief overview of how funding for health and social care services is divided federally, how one accesses different types of health and social care in Ontario, and which agencies or organizations deliver what type of care.

Federal legislation in Canada divides authority between two levels of government, and the Constitution Act of 1867 specifies the different responsibilities of the federal government and the provincial/territorial governments (Government of Canada, 1867). Health care and social care are largely the responsibility of provincial and territorial governments; thus, Canada does not have one health care system, but several single-payer universal health care systems for “medically necessary” insured services. The Canada Health Act (CHA) defines what is considered a basic or minimum level of health care that provinces and territories should provide, and increases the likelihood of compliance by providing the provinces and territories with federal funds through transfer payments, which can be withheld if certain legislative requirements under the CHA are not met (Marchildon, 2013; Campbell & Marchildon, 2007).

The CHA does not define the term “medically necessary,” nor does it provide a process for doing so. Instead, individual doctors determine what is “medically necessary” for a patient based on their medical training and the guidelines set by each province or territory (Romanow, 2002).
Provinces can elect to provide access to additional health services within their publicly funded health insurance programs; the extent of this coverage varies by province/territory, and includes a combination of non-hospital- or non-physician-based care typically targeted to specific groups (e.g., seniors or people with low incomes), such as dental care, vision care, long-term care, home care, rehabilitation, and pharmaceuticals prescribed outside of hospitals (Marchildon, 2013).

Each of the ten provinces and three territories within Canada have some form of health care system and social care system, but there is variation across these jurisdictions on what types of services are publicly funded under provincial/territorial health insurance programs beyond the basic level of insured services protected under the CHA (Health Canada, 2010). Basic social care in Canada is not legislated and universally funded like basic hospital-based or physician-delivered health care is under the CHA. Each province decides what, if any, social care services will be available to their population under their respective health insurance plans, or through other types of publicly funded programs within their jurisdiction (Hanlon, Rosenberg & Clasby, 2007).

The Ontario government funds additional health and social care above the base level of medically necessary insured services outlined in the CHA (Marchildon, 2013). Additional health care services are often provided based on a person’s needs and the availability of publicly financed services to meet those needs. Limited resources, both human (Bandali, Zhu & Gamble, 2011; Wranik, 2008) and financial (Canadian Institute for Health Information, 2015b), may limit the extent to which a service is available to meet a person’s needs within a given region. For example, a person may qualify to receive personal care in their home six hours a week, but may not receive those hours as expected or may have that time reduced if their region does not have the personnel or funds available to provide that level of care. Access to home care varies depending on local demand and supply issues in different regions of the province.

The Ontario Ministry of Health and Long-Term Care (MOHLTC) is the provincial body responsible for, "establishing overall strategic direction and provincial priorities for the province's health system; developing legislation, regulations, standards, policies, and directives to support those strategic directions; monitoring and reporting on the performance of the health system and the health of Ontarians; planning for and establishing funding models and levels of
funding for the health care system; ensuring that ministry and system strategic directions and expectations are fulfilled" (Ontario Ministry of Health and Long-Term Care, 2016).

Private providers supply the vast majority of health care in Ontario. The use of a public-contracting model, through which publicly financed health systems contract private service providers to deliver health care services, leads to substantial variation in where and how services are provided (Deber & Mah, 2014). In urban environments, there is a concentration of services available across the local health system, while in more rural environments there is less supply to meet demand for services.

The setting in which health and social care services are received indicates whether costs associated with those services will be paid by the publicly financed system or by private funds. Unlike universally covered physician and hospital-based “insured services” as outlined in the CHA (Government of Canada, 1985), additional health services can also be available for purchase on the private market. These services may be available in the community and provided by a variety of organizations operating on either a non-profit or for-profit basis.

Service providers may be publicly owned and operate on a non-profit basis, privately owned and operate on a non-profit basis, or privately owned and operate on a for-profit basis. Approximately 70% of total spending on health care services comes from public funds, and the remaining 30% is from private funds (Canadian Institute for Health Information, 2015a). Private financing includes out-of-pocket expenses, expenses covered by private insurance, or expenses covered by charity (Marchildon, 2007; Deber & Mah, 2014; Marchildon & Di Matteo, 2015).

Social care services in Ontario are funded through various sources. The provincial government provides some funding for social care services through the Ministry of Community and Social Services, but these services are mostly aimed at assisting the unemployed, people with disabilities, and in the protection of children (Ontario Ministry of Community and Social Services, 2015). Some social care services are funded in the home and community care sector through specific community services funding available through the MOHLTC portfolio (Ontario Ministry of Health and Long-Term Care, 2015a). Social care services are also funded through a combination of charity and private finance streams. If a person is unable to access publicly-funded social care, then their ability to pay for services dictates what social care they can access. This is similar for non-publicly funded health care services.
The categories covered under insured services are clarified in the CHA statement of insured services (Government of Canada, 1985); however, within provincial/territorial jurisdiction, the inclusion of services in health insurance plans can be blurry, as services such as homemaking and attendant care services involve both health and social care. The combination of both types of care required by someone living with dementia will vary based on the stage of dementia and a person’s individual characteristics, but some combination of health and social care is typically needed at each stage along the dementia continuum (Moïse, Schwarzinger & Um, 2004; Alzheimer Society of Canada, 2015b). As symptoms progress, people require higher levels of health and social care to meet their individual needs (Nowrangi, 2015; Alzheimer Society of Canada, 2015b).

As Daly (2007) explains, home care is a combination of services that straddle the line between health care and social care. She differentiates the two by identifying specific health-oriented home care and social-oriented home care services. Health-oriented home care focuses on in-home nursing, rehabilitation, and personal support services. In contrast, social-oriented home care focuses on volunteer programs like Meals on Wheels, transportation, friendly visiting, adult day programs, homemaking and home maintenance. Daly outlines two important reforms in Ontario that changed how home care services are delivered, resulting in a shift toward health-oriented home care in Ontario. The first reform transferred responsibility for the long-term care sector from the Ministry of Community and Social Services (MCSS) to the Ministry of Health (MOH) in 1990. The second was the move to a “managed competition” delivery model in 1997, which resulted in the commercialization of publicly financed home care. Daly claims that the shift in home care from social-oriented to health-oriented service resulted in a greater focus on medical home care interventions like nursing, rehabilitation, and personal support.

The impact of this today has resulted in the publicly financed home and community care system being mainly funded and managed through the MOHLTC. The MOHLTC’s mandate, to strategically plan and steward health care in Ontario, privileges access to medical home care over social home care services (Daly, 2007). This has implications for people who have both health and social care needs.
4.1.1 Ontario Legislation Governs the Provision of Care

There are several pieces of legislation in Ontario that govern health care provision in the province. This includes legislation that determines who can deliver what type of service and the methods for regulating the provision of that service. There are 26 health regulatory colleges in Ontario, with the legal responsibility to regulate their respective members as set out in the Regulated Health Professions Act (Ontario Government, 1991). Regulated health professions in Ontario include audiology and speech-language pathology, chiropody and podiatry, chiropractic, dental hygiene, dental technology, dentistry, denturism, homeopathy, kinesiology, massage therapy, medical laboratory technology, medical radiation technology, medicine, midwifery, naturopathy, nursing, occupational therapy, opticianry, optometry, pharmacy, physiotherapy, psychology, psychotherapy, physicians and surgeons, respiratory therapy, and traditional Chinese medicine (Ontario Government, 1991). The members of each of these professions are required by law to self-regulate through an established regulatory college; each college sets and enforces standards and guidelines for the practices and conduct of their members, and ensures that members meet their training and educational standards before they can practise their profession (Federation of Health Regulatory Colleges of Ontario, 2016).

Relatedly, the Social Work and Social Service Work Act (Ontario Government, 1998) requires that the profession of social work and social service work regulate the provision of social care provided by their members.

It is important to note that although these health and social care professionals are regulated, it is non-regulated personal support workers (PSWs) who deliver much of the ongoing, day-to-day health and social care services to people with dementia. This includes providing personal care, such as dressing, bathing, toileting, and transferring, as well as social care, such as emotional and mental support, and companionship to reduce social isolation (Ontario Personal Support Worker Association, 2016).

The Home Care and Community Services Act (Ontario Government, 1994) outlines what is to be considered home and community care, provides a bill of rights for people receiving home and community care services, and outlines rules that govern approved agencies and service providers. Home and community care services are identified as encompassing services of community support, homemaking, personal support, and professional services not accessed through a
hospital. Within the Act, community support services include the provision of meals, transportation, caregiver support, adult day programs, home maintenance and repair, friendly visiting, security checks or reassurance services, and social and recreational services. Homemaking services include housecleaning, laundry, shopping, banking, menu planning, and meal preparation. Personal support services include personal hygiene activities, routine personal activities of living, and assisting and/or training someone in these activities. Professional services include nursing, occupational therapy, physiotherapy, social work, speech-language pathology, and dietetic services. At the time of writing, publicly financed home and community care and long-term care were accessed through a set of regionally based Community Care Access Centres (CCACs) (Ontario Ministry of Health and Long-Term Care, 2007a). CCACs assess a person’s needs and allocate publicly financed home and community care services as well as manage a person’s placement on long-term care home wait lists (Ontario Association of CCACs, 2013). They also refer people to private-payer services that a person can purchase over and above what may be funded publicly. The services allocated are delivered by private for-profit or not-for-profit service provider organizations.

Long-term care homes are regulated by the Long-Term Care Homes Act (Ontario Government, 2007) and are expected to provide care to people with higher needs who can no longer live independently in another setting. The Act is prescriptive and comprehensive, with regulations spanning the physical building requirements as well as care provision and safety requirements. Homes can be owned by municipalities, not-for-profit organizations or for-profit entities, and receive government funding to provide higher levels of care, including 24-hour nursing care, to residents than what is publicly financed and available in the home and community care sector. Residents pay for their room and board (if financially able), and the MOHLTC provides funding for some health and social care services beyond the “insured services” protected by the CHA (Ontario Ministry of Health and Long-Term Care, 2015a). Waiting lists to access long-term care homes are typically long. In 2013/2014, people waited a median of 108 days to be placed in a long-term care home (Health Quality Ontario, 2016). The Ontario Long-Term Care Association (2015) reports that in 2015, 62% of residents in long-term care had dementia.

There is a distinction between long-term care homes and retirement homes in Ontario. Retirement homes provide seniors who need minimal support to live independently with a residence in a communal setting. They are privately owned by either non-profit or for-profit
entities and do not receive government funding to the extent that long-term care homes do, nor are they intended to provide 24-hour nursing care by definition (Ontario Ministry of Health and Long-Term Care, 2015a). Residents pay for room and board, and they have the option of paying for additional services under assisted living categories. The Retirement Homes Regulatory Authority oversees retirement homes through licensure, as established by the Retirement Homes Act (Ontario Government, 2010). Although retirement homes are not intended to replace or replicate the high level of care available in long-term care homes (Ontario Ministry of Health and Long-Term Care, 2015a), the divide between the two is not so clear in practice.

Across Canadian jurisdictions, there have been changes made to the structure of health systems by creating regional health authorities or networks that are responsible for allocating health resources and planning health initiatives locally (Marchildon, 2013). The rationale behind regionalizing the allocation of resources supports the idea that people making decisions who are closer to the “local level” can better understand and respond to the health needs of that jurisdiction’s specific populations. Within a province there may be differences in a person’s needs depending on where they reside. For example, populations in more rural parts of a province tend to have a higher proportion of people over age 65 due to the outmigration of younger age groups (Moazzami, 2014; Dandy & Bollman, 2008).

Ontario moved to establish 14 Local Health Integration Networks (LHINs) in 2005 as part of the Ontario government’s agenda to transform Ontario’s health care system from one that was siloed across sectors to a more integrated approach across sectors and service providers (Bhasin and Williams, 2007; Gutmanis et al., 2015). LHINs have taken over key responsibilities from the MOHLTC to oversee and manage the delivery of some health care within specified regions (Bhasin & Williams, 2007). These responsibilities include promoting the integration of the local health system, improving the coordination of certain health services, improving access to health services, and enhancing the continuity of health care (Local Health System Integration Act – see Ontario Government, 2006). Public hospitals, CCACs, community mental health and addictions agencies, community support services organizations, community health centres, community-governed family health teams, and long-term care facilities fall under the auspices of the LHINs (Local Health Integration Act, 2006; Bhasin & Williams, 2007). In this capacity, the LHINs plan, fund, and monitor these services. At the time of writing, the LHINs did not have responsibility for pharmaceuticals, fee-for-service physician services and non-community
governed primary care models, dentists, chiropodists, optometrists and corporations of these health professionals, or public health, ambulance services, and laboratories (Local Health Integration Act, 2006; Bhasin & Williams, 2007). On June 2, 2016 the Ontario government introduced legislation that would give LHINs an expanded role. If passed, the new legislation would amend the Local Health System Integration Act, 2006 and the Home Care and Community Services Act, 1994, among other statutes (Ontario Government, 2016).

The LHINs and the MOHLTC enter into accountability agreements; these contain funding amounts for the LHINs, service standards and targets that must be achieved, plans for spending allocated funds, and expected health care and system outcomes (Bhasin & Williams, 2007). The LHINs also enter into service accountability agreements with each health service provider that they fund. The Local Health System Integration Act (2006) stipulates that LHIN boundaries will not affect where a person receives their health services. The exception to this is publicly financed or otherwise subsidized home and community care services accessed by the public through CCAC referrals. CCAC regions are defined by clear boundaries, and as mentioned in section 4.1, receiving the allocated services may depend on if trained staff persons are available in the region (Bhasin & Williams, 2007).

While the regulation of health care in Ontario is more detailed than described in this section, for the purposes of this thesis it is simply important to identify that there are major differences between the regulation of health care as compared to social care, and that the structure these regulations create has an impact on how dementia care is accessed and received in Ontario.

4.2 Dementia Care Services in Ontario

This section provides an overview of the types of services available to people with dementia in the public and private spheres of health and social care in Ontario. The information here is intended to summarize what is available in Ontario and is not meant to be exhaustive.

As people with dementia progress along the aforementioned continuum, various health and social care services are needed and recognized as best practices in dementia care (Moïse, Schwarzinger & Um, 2004; RNAO, 2003/2006; Rivard & Puxty, 2009). Current medical approaches to dementia care in Ontario are often challenged by evidence-based social care practices, or hybrid approaches that produce better outcomes for this population (Gutmanis et al.,
2015), but do not typically fall within the MOHLTC funding envelope due to the non-medical nature of these interventions. This includes services like adult day programs (which have daily fees), and other social inclusion and activity-based services that are important for providing a person with a social outlet to combat the isolation that often occurs with a diagnosis of dementia (Hughes, 2012).

The Toronto Central LHIN, responsible for the planning and integration of health services across much of the city of Toronto, commissioned a project in 2010 that would recommend ways to improve access and navigation of dementia services across Toronto. The project goals were to "develop common definitions for specific services, approaches and care paths for agencies serving people with dementia, develop training models for service agencies using culture and language-specific training tools, identify community support services and service gaps in dementia care, and map current referral methods and access points for dementia services" (Morton, 2010, p. 9). This project identified the definition of core dementia services as having two key components:

1. Core dementia services are central to the care and well-being of people with dementia and their caregivers.

2. Core dementia services are delivered throughout the continuum of dementia by staff with dementia-specific training, knowledge and skills.

The core dementia care services they identified include: (a) primary care and related memory clinics, (b) dementia-specific education, (c) home services, (d) support groups, (e) dementia-specific respite services, (f) adult day program, (g) assisted living, (h) dementia or behavioural units within long-term care or other residential care facilities (Morton, 2010). Other services they identified that people with dementia may need include: (j) general nursing (k) social work services, (l) specialized geriatric services, (m) palliative care services, and (n) transportation services (Morton, 2010).

Each of these are described in more detail below. Core dementia care services in Ontario include:

(a) Primary care and related memory clinics: Primary care services accessed on their own or in combination with the services available at a memory clinic. These outpatient clinics offer diagnosis, care and support to people who are experiencing memory disorders or some type of
probable dementia. These clinics can be stand-alone, or held in existing physician offices, hospital clinics, or nurse practitioner-led clinics and are funded publicly through existing primary care resources. Multidisciplinary approaches are typically used to provide more comprehensive support to the patient. These clinics assist people in the diagnosis and early stages of dementia.

(b) Dementia-specific education: Education for people with dementia, caregivers, and the broader community. These may include print and online materials, formal instruction, interactive workshops, or forums. Education is accessed throughout all stages of the dementia continuum and through a variety of sources, including government, health charities, health care providers, professional organizations, and scholarly journals. Access is common via the internet, CCAC referral, or direct contact with a dementia education provider. Information is commonly shared freely, or is accessible through charitable channels.

(c) Home services: Health care, social care and support services that are delivered in the home to assist people remain in their homes if possible. These services can be purchased directly through a service provider organization, or can be provided by the publicly-funded system through the CCACs. For people with dementia, home services can include:

i. Dementia-specific friendly visiting: Regular home visits from a dementia-trained volunteer with the goal of providing companionship and social support. Most often useful for people with dementia who live alone. Can include attending with the person outside of the home to complete tasks like shopping or to attend social activities.

ii. Home help/Homemaking: Assisting people with dementia at home with routine household activities, including light housekeeping, laundry and light meal preparation. May include assistance with banking, shopping and errands, or shopping on the person's behalf.

iii. Personal Care/Personal support: Assisting a person with dementia with personal hygiene and other activities of daily living. May include bathing, hair, skin and mouth care, help with toileting, getting dressed, feeding transferring and positioning, medication reminders, light exercising and escorting to medical appointments.

(d) Support groups: A group of people with common experiences or concerns who provide each other with encouragement, comfort, and advice. Support groups exist for people with dementia and for families and caregivers, either together or separate of each other. Groups may be formally organized by community organizations and charities, or develop organically and are
available without a fee. Online forums are also used as support throughout the dementia continuum.

(e) Dementia-specific respite: Support services for people with dementia that provides primary caregivers with temporary relief of their caregiving duties. Respite may include adult day programs, in-home respite, personal care, homemaking, safety checks or social interaction activities. These services are helpful for caregivers who support someone with dementia in the intermediate and late stages of the continuum. Respite can be purchased directly through a service provider organization, or can be provided by the publicly-funded system through the CCACs.

(f) Adult day programs: Supervised and supported social and recreational activities provided at a location outside the person with dementia's home. Programs generally include meals, transportation to the program, and some personal care. Programs may include light physical activity, assistance with activities of daily living, and minor health care assistance. Most day programs run from 6-8 hrs on week days, but some provide overnight stays for people with dementia to provide additional respite to the primary caregiver. These programs are available through community organizations and long-term care homes, and can be accessed directly with a community organization or through CCACs.

(g) Assisted-living for person with dementia: Privately-accessed and funded designated housing within a retirement home that provides services and support in congregate or individual accommodation, and can meet a wide range of needs of people with dementia. Services may include individual assessment, planning, and a choice of service options; homemaking, light housekeeping, shopping, laundry, personal support, medication monitoring, social activities, nutrition programs, security checks, and planning and coordinating other services that enable independent living. Support services may be available on a 24-hour basis.

(h) Long-term care: Within long-term care homes, there are sometimes specialized units or programs for people with dementia. All are tailored to people in the intermediate or late stages of dementia and are accessed through a long-term care referral from a CCAC. They include,

i. Dementia unit: A unit within a long-term care home specifically devoted to the care of persons with dementia. These units are generally secure (locked) and they may be further subdivided based on the level of care needed.
ii. **Behavioural unit:** Units specifically devoted to the care of individuals with severe behavioural issues as a result of dementia and/or other neurological or mental illnesses. Generally, these units are secure and provide an array of interventions based on need. Services may include assessment, on-going care planning, interventions, medication and behaviour management.

iii. **In-patient behavioural assessment unit:** Units that provide an interdisciplinary evaluation of people with dementia who have complex or severe behavioral issues. The comprehensive treatment plans take into consideration the needs of both the client and caregiver, in order to develop a discharge plan that includes education and referral to community resources. Services may include a diagnostic work-up, using various behavioural tools to make a diagnosis, develop a care plan/intervention, and provide medication management. They may also include education and transitional plans to discharge patient back to the community/home. (Morton, 2010)

In addition to core dementia care services, Morton (2010) identified that people with dementia may access non-dementia specific services that can be considered complementary in nature to dementia-specific services. These include:

(j) **Nursing:** Trained professionals providing assessment, care and treatment of health condition and health promotion, to reach or maintain optimal health. Services may include supportive, preventive, therapeutic, palliative and rehabilitative nursing, as well as specialty nursing services and wound care. Nursing services are accessed throughout the dementia continuum in hospitals, in long-term care homes, through CCAC referral for home care or through other clinics or community organizations. Public funds are used for nursing services provided through the home and community care and long-term care sectors, but private nursing can be purchased directly.

(k) **Social Work:** Trained professionals providing support and counselling to help people develop and maintain the skills and abilities needed to function as independently as possible. This may address a variety of social, economic and personal needs, including adjusting to chronic illness, elder abuse, providing care to a senior, advocacy, service referral, information and education. Social Work services can be accessed through CCACs, community services organizations, through direct contact with a practitioner or through hospital and long-term care services.

(l) **Specialized geriatric services:** A variety of health care services that diagnose, treat and rehabilitate frail seniors with complex medical, functional and psychosocial issues. Services are provided in the senior’s home, in inpatient or clinic /outpatient settings by a multidisciplinary
health/social team. Services are accessed with public funds through physician referral, CCAC referral, through hospitals or outpatient clinics. Self-referral is possible in some instances.

(m) Palliative care: A combination of therapies delivered by a multidisciplinary health/social team, intended to comfort and support individuals who are dying from a progressive, life-threatening illness, as well as their families. Focus is on minimizing pain and maintaining quality of life. Services may include hospice care, plans for palliative care unit admission, Do Not Resuscitate orders, living wills, and bereavement support for caregivers. Not all palliative care services will serve people with dementia. Palliative care is essential when people are at the end-of-life stage of the dementia continuum, and accessed through hospice or hospital facilities. Public funds pay for medical costs, some home care services, some medications; private funds pay for services, medications, and related supplies not covered by public funds.

(n) Transportation: Rides for seniors who do not have their own method of transportation. Transportation is provided by staff or volunteers. Rides are provided to medical or therapy appointments, shopping and various social activities and programs. Services may include escort assistance for frail seniors who need more “hands-on” help and transfer support. Transportation services are often accessed after a person's licence to drive is revoked, and this can happen at any point along the dementia continuum. Transportation services can be accessed directly with private funds, or through charitable and community organizations using donations or government funding for specific programs. (Morton, 2010)

A full list of core services and other services in Ontario is available in appendix D, with an accompanying definition, description, and a delineation of how a person accesses services, how the services are financed, and the location of delivery for services.

People with dementia primarily receive care in their homes, in the community, or in long-term care homes (Weber, Pirraglia & Kunik, 2011); however, providing best practices in dementia care as described in section 2.3.2 is an ongoing challenge in the home, community and long-term care sectors. A search of the literature identifies three main factors that diminish a provider’s ability to maintain consistent best practices: (1) having an insufficient number of staff (Petch, Tierney & Cummings, 2013; Duffin, 2012), (2) insufficient skill sets among staff (Janzen et al., 2013; D’Hondt et al., 2011), and (3) a narrow definition of health care in Canada (Health Canada, 2010; Deber & Mah, 2014).
Providers of long-term care and home care have consistently said they do not have enough funding to hire enough direct-care staff to meet demand. They argue that in order for each worker to have the time required to develop an individualized approach that can identify triggers for responsive behaviours, there should be more staff on each shift in order to reduce the ratio of patients to workers. As Petch, Tierney and Cummings (2013) documented, the time available for staff to provide direct services to people in their care is limited by the number of people assigned to them and the level of support needed by each person in their care. Discussions of staff-to-resident ratios in long-term care facilities are ongoing across jurisdictions, with professional organizations like the Royal College of Nursing in Great Britain (Duffin, 2012) and jurisdictional task forces like Nova Scotia’s 2002 task force on resident/staff ratio in nursing homes, advocating for the establishment of minimum staff-to-resident ratios. The scarcity of resources across health systems has resulted in high caseloads and less time available for workers to provide individual and person-centred care (Petch, Tierney & Cummings, 2013; Auditor General, 2010).

Even with an increased number of staff available to provide care, the training that they possess must be considered when assessing barriers to implementing dementia care best practices. Part of the challenge in providing best practice care is that dementia care is not a required part of training within existing certificate programs that provide training to support workers, and these staff provide the majority of direct personal care to people living with dementia in the intermediate to later stages of the dementia continuum. Personal support workers, home health aides, and health care aides (Berta et al., 2013) are not required to receive training specific to dementia and responsive behaviours before working with this population. Janzen et al. (2013) and D’Hondt et al. (2011) have each examined how a lack of specialized training in dementia care is a barrier to providing quality assistance to people with progressive dementias. Existing dementia care training programs are aimed at the post-certificate cohort, and accessing specialized training like P.I.E.C.E.S. (McAiney et. al., 2007), U-First! (Alzheimer Society of Ontario, 2015), GPA (Alzheimer Society of Oxford County, 2015) or Montessori (Huntsman, 2014) requires that staff be temporarily removed from work rotations. Additional workers would need to replace staff members who are receiving training.

The defining feature of staff training programs on dementia care and responsive behaviours is that they emphasize an approach to care that could be considered more of a social care service
than a health care service. All training programs assist the worker in learning how to recognize triggers, distract the person and de-escalate the situation, and take the time to get to know the person so the worker is able to develop individualized care plans and approaches that can be communicated to other staff.

Overall, the basic element affecting these factors seems to be a lack of public funds and the human resources to meet demand. Better implementation of best practices in dementia care would require increasing the number of staff available to provide care in order to decrease caseloads and allow additional time for staff-patient interactions. It would also require funds to hire qualified workers on a replacement basis in order to train existing staff on approaches to best practices in dementia care. This would require additional government funds. Health systems across Canada have been faced with fiscal (Canadian Institute for Health Information, 2015b) and human resources challenges (Bandali, Zhu & Gamble, 2011; Wranik, 2008) that have had an impact on the ability of providers to meet best practice guidelines in dementia care. Health care can be expensive, and within publicly funded systems, cost containment is seen as critical to the sustainability of such health care systems (Birch et al., 2015). Since the 2009 recession, provincial governments in Canada have focused on restraining program spending to manage budgetary deficits, and health spending has been slower than the growth in the overall economy (Canadian Institute for Health Information, 2015b, p. 7). Governments are trying to do more with less, looking for efficiencies, and identifying ways to increase the capacity of the system to meet demand while reigning in health care spending. Balancing the needs of the patient with the ability of the health system to fund needed services is a necessary consideration and an ongoing challenge for providers when implementing best practices.
Chapter 5
Preceding Policies and the BSO Initiative

This chapter explores policies that preceded the BSO initiative, presents contextual information about how the BSO initiative relates to these other policies, and provides an overview of the activities associated with the BSO framework.

5 Preceding Policies

Three policies were identified in the literature as being related, either because of timing or target population, to the development of the BSO initiative: Ontario’s Strategy for Alzheimer Disease and Related Dementias, Aging At Home strategy, and Emergency Room/Alternate Level of Care strategy. This chapter will explore each one as they relate to the others, and explain the purpose and contents of the BSO initiative and resulting framework of care.

This thesis expects that the policies that preceded BSO would have an influence on the BSO initiative in some way, since these policies all targeted seniors or a subset of seniors with dementia. These three policies focused on various aspects of the same problem: the need to provide ongoing care to an aging population within a system originally designed to respond to acute and episodic care needs.

In Ontario, the priorities of the MOHLTC have focused on reducing the annual growth rate for health spending without drastically altering services. To do this, the MOHLTC’s mandate highlighted a need to find efficiencies within the existing health care system (Ontario Ministry of Health and Long-Term Care, 2012). One approach involved reducing effort duplication by integrating service provision, and coordinating care in a way that focused on the patient across the various health care sectors. The MOHLTC asserted that by doing this, patient outcomes would improve while health care spending would be reduced. Seniors with chronic and co-morbid health conditions were identified as a population of interest, so the provincial government developed the following three policies in order to target its strategies toward improving the care provided to this population.
5.1 Ontario’s Strategy for Alzheimer Disease and Related Dementias (Alzheimer Strategy)

The Ontario Alzheimer strategy was the first policy in Ontario that explicitly targeted the growing number of people with dementia who were in need of support (Alzheimer Knowledge Exchange [AKE] 2015; McAiney, 2005). Implemented between 1999–2004, this policy emphasized: increasing awareness of dementia among the general public; increasing respite available to caregivers; increasing support for people with dementia and their families; and staff and physician training in dementia issues. The strategy coupled training with the establishment of specialized geriatric services and increased psychogeriatric consulting resources in long-term care homes to provide staff with support and access to education; it also focused on researching the needs of caregivers and enhancing intergenerational connections between high school students and people with dementia in long-term care homes (AKE, 2015; McAiney, 2005).

Upon its 2005 completion, this strategy was deemed successful in achieving many of the goals established within the above focus areas (McAiney, 2005). Although the evaluation indicated that the services put in place through this strategy were better meeting some of the needs of people with dementia and their caregivers, the strategy itself was not renewed past the initial implementation period for reasons unknown. However, base funding was added on a permanent basis for: Psychogeriatric Resource Consultants, Public Education Coordinators in local Alzheimer Societies, and enhancements to respite services for caregivers. In addition, specific services funded through this strategy – for example, funding for Regional Geriatric Programs and professionals known as psychogeriatric resource consultants – remain operating in the system today. Funding is possible for this through allocations made within each LHIN (Regional Geriatric Programs of Ontario, 2016).

5.2 Ontario’s Aging at Home Strategy (AAH) and Emergency Room/Alternate Level of Care (ER/ALC) Strategy

As the LHINs were fully implemented in 2007, the Ontario government announced that the Aging At Home (AAH) strategy would establish an integrated system of community-based services to assist seniors who wanted to remain in their homes for as long as possible. To do this, the government initially committed $700 million; this was expanded to $1.1 billion over four years in 2009 (Ontario Ministry of Health and Long-Term Care, 2010). The funding was
intended to increase the availability of socially oriented homecare services, including meal preparation, transportation, friendly visiting, adult day programs, caregiver relief and support, as well as homemaking and assistance with other IADLs (Ontario Ministry of Health and Long-Term Care, 2010). The services available through this strategy straddled the line between health care and social care.

The government cited increased efficiency and quality of services as well as lowered health care costs as the drivers of the AAH strategy (Ontario Ministry of Health and Long-Term Care, 2010). LHINs were directed to identify local priorities through which to expand home and community services for seniors living in their own homes, and to focus on keeping people in their homes in an effort to avoid residential long-term care by preventing deterioration of their conditions. The government rationalized this approach by claiming that a lack of publicly funded home care increased the use of emergency services, resulted in delayed hospital discharges, and placed more demand on residential long-term care facilities (Costa & Hirdes, 2010; Luppa et al., 2008).

The number of days a patient stays in an acute care bed waiting for another level of care (like placement in a long-term care home, admittance to a rehabilitation program, or being discharged home with or without home care supports in place) increases wait times for others to be admitted to hospital from the emergency department (Canadian Institute of Health Information, 2009b and 2012). This was the rationale used for the directional shift from the AAH strategy to the ER/ALC strategy. The funding that flowed through the AAH strategy was intended to increase the capacity of home and community care for seniors who were currently at home and wished to stay there. In years one and two of AAH, 20% of funding was aimed at increasing the home care available to patients being discharged from hospital, and 80% of funding aimed to increase access to home care for seniors already in the community but at risk of needing hospital or long-term care if they did not receive support (Auditor General, 2010). In the third year of the AAH strategy, however, the MOHLTC announced that 100% of funding would be aimed at reducing ER wait times by focusing on moving people occupying acute care beds who no longer needed acute care to an appropriate alternate level of care (Ontario Ministry of Health and Long-Term Care, 2010). This new emphasis was the purpose of the ER/ALC strategy launched in 2008, a year after the AAH strategy (Ontario Ministry of Health and Long-Term Care, 2008). Because the timing of these two strategies overlap, it is difficult to ascertain how they were intended to
function together; however, it was clear by year three of the AAH strategy that the focus had become one of substituting acute care with the intention of safely discharging people from acute care hospitals to free up a bed for someone else.

The target population changed from people who needed help to remain at home, as seen in AAH, to people who needed help returning home from hospital (Ontario Ministry of Health and Long-Term Care, 2008). This refocusing was ostensibly to decrease the length of wait times for emergency and hospital admissions and thereby the strain facing hospitals and long-term care homes.

At this time there was no direct connection made between increased rates of ALC days and people with dementia, even though one out of four Canadian seniors occupying a hospital bed who no longer required acute care in 2009/2010 had a diagnosis of dementia (Canadian Institute for Health Information, 2009a). Hospital stays involving clients with dementia were twice as long on average than for seniors without the disease (median of 20 days versus 9 days) (Canadian Institute for Health Information, 2009b). The beds in hospitals are for the treatment of acute needs, and are inadequate to provide long-term care to patients waiting for an alternate level of care (Canadian Institute for Health Information, 2009b). The longer lengths of stay for people with dementia designated as requiring ALC have since been identified as having a direct relation to persons exhibiting responsive behaviours (Ontario Behavioural Support System Project Team, 2010).

5.3 Behavioural Supports Ontario

A subpopulation of seniors who were not adequately targeted through Ontario’s Alzheimer strategy, AAH strategy, or ER/ALC strategy were those with responsive behaviours (Gutmanis et al., 2015). These people were identified as high-service users that the current system was not serving well. The system-wide response to this population up to that point was identified as insufficient to meet their needs. Behavioural Supports Ontario (BSO) was an initiative that was designed to improve the system of care for seniors with responsive behaviours in the province of Ontario. Developed and implemented between 2009 and 2013, this policy aimed to redesign Ontario’s health system to respond more appropriately to people exhibiting responsive behaviours.
BSO was not a service in and of itself, but the initiative provided a provincial framework for care that would guide changes in service delivery from the status quo to an approach more amenable to the needs of those exhibiting responsive behaviours. The BSO initiative focused on adding expertise into the existing health system to aid in behavioural support and education, providing staff with access to information on managing responsive behaviours, providing single points of contact for patients in crisis, and using knowledge translation to aid in the transfer and exchange of information across sectors and LHIN boundaries (Gutmanis et. al. 2015).

BSO was developed as a phased approach in which a “Framework for Care” was developed in the first phase, and then four LHINs implemented the framework in phase two. These early-adopters included the North Simcoe Muskoka LHIN, Central East LHIN, South East LHIN, and Hamilton Niagara Haldimand Brant LHIN. The third phase involved provincial implementation of the framework, which integrated the remaining ten LHINs (Ontario Behavioural Supports System Project Team, 2010).

The BSO initiative is built upon three foundational pillars:

1. system management: coordinated cross-agency, cross-sectoral collaboration and partnerships based on clearly defined roles and processes to facilitate “seamless” care specifically for people with responsive behaviours;

2. intersectoral interdisciplinary service delivery: interagency collaborative teams and services that bridge sectors, thereby mobilizing the right services and expertise to provide for and enable improved transitions;

3. knowledgeable care team and capacity building: (1) strengthen capacity of current and future professionals through education and focused training to transfer new knowledge and best practices; and (2) develop skills and effective use of quality improvement tools and processes for continuous service improvement within and across sectors (Ontario Behavioural Support System Project Team, 2010).

The Coordinating and Reporting Office (CRO) was an advisory body that provided provincial oversight. Each LHIN completed a capacity assessment and developed an “action plan” that was reviewed by the CRO in relation to the three pillars before implementation commenced. Each LHIN created a Behavioural Supports Implementation Committee that identified lead organizations/personnel in each sector of the health system with which to develop formal and
informal partnerships, seamless processes, and identify common tools and best practices. In order to avoid service duplication within the LHIN, each network was to leverage existing knowledge pathways, initiatives, education programs, and expertise in their regions. For a schematic of BSO reporting and accountability processes, see appendix E.

Health service providers (HSPs) who participated in the BSO initiative spanned the areas of long-term care, acute care (hospitals), and home and community care. Each HSP within each LHIN participating in the BSO initiative used the BSO Capacity Building Roadmap (Behavioural Supports Ontario [BSO], 2012e) to organize their processes. The Roadmap included guidance on using BSO Health Human Resource funding to hire staff to support the initiative; it also assisted HSPs in identifying necessary qualifications in new hires and “how” to go about getting new hires with the needed skill sets. The hiring process was guided by three broad questions: what universal skills should the new hire have? What regionally specific skills are required to execute the LHIN’s action plan? And what individual skills needed by the new hire will be dictated by their unique complement of skills and capacity they bring to the job?

In addition to hiring new staff, the BSO initiative supported the ongoing education of both new and existing staff, since best practices training in dementia care is not currently a requirement to work in the field. To do this, the BSO Provincial Education and Training Committee adapted the existing Dementia Educational Needs Assessment (McCainey, Hillier, Ringland, & Cooper, 2009) to a system-wide framework titled the “Behavioural Education and Training Supports Inventory (BETSI): A Decision Making Framework” (see BSO, 2012d) with a corresponding BETSI tool for HSPs to decide which existing training programs would be right for their needs (i.e., P.I.E.C.E.S, U-First!, GPA or Montessori). The development of the BETSI framework aligns with BSO’s Pillar 3, “knowledgeable care team and capacity building,” by assisting HSPs in determining whether their staff need education, whether their staff are able to support practice change, what educational opportunities are available to them, and how these programs align with the BSO target population, core competencies and service functions (BSO, 2012d). HSPs were to use the BETSI framework during the influx of newly hired staff, and during times of turnover to support ongoing service provision and the learning needs of staff.
The table below identifies the different activities that the LHINs embarked on. Note that LHINs’ involvement in these activities varied based on their needs as identified by each implementation committee. Of the 14 LHINS, the number of LHINs that applied each activity is indicated.

Table 6-1: BSO Activities (BSO, 2013)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Explanation of Activity</th>
<th>Total number of LHINs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile team – lead/host model</td>
<td>A lead organization recruits, trains, and delivers interdisciplinary outreach support in care settings throughout a region. Usually, the lead is a LTC home delivering care to residents in other homes (subject to terms in a formal memorandum of understanding). Support is scheduled or episodic, and includes skill-building mechanisms for other staff and family in the resident’s circle of care.</td>
<td>6</td>
</tr>
<tr>
<td>Mobile team – decentralized staffing model</td>
<td>On-site nurses or PSWs dedicated to behavioural issues in a LTC home. This model is common where existing mobile interdisciplinary resources are available to some or all of the participating LTC homes but added on-site support is needed. In some LHINs, the homes that receive BSO-funded staff assume team leadership duties for a cluster of other nearby LTC homes.</td>
<td>7</td>
</tr>
<tr>
<td>Capacity enhancement training program</td>
<td>Comprehensive responsive behaviours training strategy for new and existing staff in LTC, community and acute-care sectors.</td>
<td>14</td>
</tr>
<tr>
<td>Other mobile or regional specialist roles</td>
<td>Psychogeriatric resource consultants (PRCs), geriatric psychiatrists, and others intended to augment existing local teams or serve as a specialist resource for existing service mix in a given LHIN. These PRCs were initially funded under the Ontario Strategy for Alzheimer Disease and Related Dementias.</td>
<td>12</td>
</tr>
<tr>
<td>Behaviour support champions in LTC</td>
<td>Specialized role for current staff within a LTC home. Responsible for leading, coordinating and disseminating effective strategies for responsive behaviours in a LTC home.</td>
<td>5</td>
</tr>
<tr>
<td>Behavioural support unit</td>
<td>Transitional specialized support for persons whose responsive behaviours have become unmanageable in their current setting and for whom available supports have not been successful in managing the responsive behaviours of concern. The goal of the unit is to stabilize responsive behaviours and support transition until the resident returns home (to the community or a LTC home). Unit provides a higher-level support model than what is currently available in LTC homes. Average length of stay is five months, but individual behavioural support units set parameters based on resources available.</td>
<td>5</td>
</tr>
<tr>
<td>Activity</td>
<td>Explanation of Activity</td>
<td>Total number of LHINs</td>
</tr>
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<tr>
<td>Centralized access (one number to call)</td>
<td>Centralized access to the BSO mobile teams and other behavioural support services through a single phone number. Includes risk screening, triage, and referral to other appropriate services.</td>
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</tr>
<tr>
<td>System navigator</td>
<td>Dedicated coordinator responsible for planning appropriate complementary services throughout a person’s journey. Includes centralized access to BSO resources. Could include short-term support by an intensive geriatric services worker until one or more referrals is complete.</td>
<td>4</td>
</tr>
<tr>
<td>Common assessment toolkit</td>
<td>Development of a common minimum set of assessments (standardized assessments) for people with responsive behaviours across the service continuum. The toolkit outlines service events, process steps, common assessment tools, and pathways. The local mobile support team provides education to service providers on the use of the toolkit, and interpretation and application of the tools and pathways.</td>
<td>5</td>
</tr>
<tr>
<td>Integrated care team</td>
<td>Realigning existing resources in a community and/or in LTC to ensure collaboration and seamless care transitions (incl. CCAC, hospital, LTC home, community mental health centre).</td>
<td>8</td>
</tr>
<tr>
<td>Complex case resolution</td>
<td>Forum for CCACs, community service sector, primary care organizations, Alzheimer’s Societies and others to discuss shared clients in the community whose multiple complex needs require a coordinated response.</td>
<td>5</td>
</tr>
<tr>
<td>Primary care toolkit</td>
<td>New toolkit containing assessment and screening tools for early detection and management of individuals with responsive behaviours.</td>
<td>3</td>
</tr>
<tr>
<td>New tools, clinical pathways, and value-stream maps</td>
<td>Tools designed to assist in system redesign efforts to realign, optimize or better integrate the existing local service mix.</td>
<td>14</td>
</tr>
<tr>
<td>Online behavioural supports portal</td>
<td>Online collection of local behavioural supports available.</td>
<td>2</td>
</tr>
<tr>
<td>Visual communication board</td>
<td>White boards to communicate care plans in LTC homes.</td>
<td>2</td>
</tr>
<tr>
<td>Presentations and outreach</td>
<td>Presentations about BSO and outreach across sectors to spread information on the initiative.</td>
<td>14</td>
</tr>
</tbody>
</table>

The variety of activities associated with the BSO initiative, as presented in table 6-1, may appear to overlap with or duplicate other activities. For example, the mobile teams were deployed in two different ways, depending on a LHIN’s allocation of BSO funds and the needs of the health service provider (often a long-term care home). The lead/host model established one team for a given geographic or needs-based area, and that team would respond when called upon by a long-
term care home or home care service provider. In comparison, the decentralized staffing model for mobile teams inserts a trained BSO staff member into the long-term care home or home care provider network; they would normally only provide BSO specialist services to the long-term care home or home care provider they were working for. Some LHINs decided that mobile teams using the lead/host model fit their regional needs, while others determined that the decentralized staffing model would better serve them.

All LHINs participated in a process known as value-stream mapping, which involved documenting and analyzing current service delivery processes to people in long-term care or the community who have responsive behaviours, in order to improve the flow of information or resources required to provide quality care to people. They also participated in developing new tools for assessment, documentation and complex case resolution, as well as the development of clinical pathways to guide transitions between various levels of care (e.g., from hospital to long-term care home). All LHINs also participated in the capacity enhancement training program, which provided specialized training in addressing responsive behaviours to new and existing staff in long-term, community and acute care sectors.

All other BSO activities were engaged in by some, but not all, LHINs. This was due to the results of LHIN-level assessments intended to identify local resources and existing services, identify gaps in the services available, and select the BSO activities that would assist a given LHIN region in meeting its BSO objectives. Since no two LHINs engaged in the exact same BSO activities, it allowed for regional flexibility on activity engagement and implementation.
Chapter 6
Methodology

Chapter 6 details the methods used to collect primary data from key informants and secondary data from existing documents, as well as the method used to analyze this data.

6 Methods

This thesis used qualitative case study methodology to study the development and implementation of the BSO initiative (Neuman, 2006). In order to understand what led to the development of BSO, the researcher began by identifying information that was publicly available on the initiative, to gather a knowledge base from which to build interview questions. Sources of data included publicly available documents and key informants, as explained below. This research received approval by the University of Toronto's Health Sciences Research Ethics Board before data collection commenced.

6.1 Data Sources

Two sources of data were used in data collection: (1) information gathered through the analysis of existing documents developed during the design, implementation, and early evaluation of BSO; and (2) information gathered through semi-structured interviews with key informants.

6.1.1 Documents

There were several documents that related to the BSO initiative identified as potentially having information needed to complete the research. Eligibility criteria was developed to sort them. In order to be included in the list of data sources for analysis, the document had to be directly connected to BSO’s development and/or implementation process; and be accessible to me either publicly using the Google search engine or through the University of Toronto library system. Documents were identified using the following search terms:

- behavioural supports Ontario
- behavioural supports
- responsive behaviours Ontario
- behavioural support system
The search term results included sources not directly connected to the BSO initiative, but only documents directly connected to the BSO initiative were included as data sources. The results of this initial search, which began in 2011, identified:

- 14 Local Health Integration Network (LHIN) action plans and accompanying appendices;
- a policy analysis and implementation discussion paper that complemented Dudgeon & Reed (2010). Retrieved from [http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-Support-System.aspx](http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-Support-System.aspx);
- a project summary of the BSO initiative, retrieved from [http://brainxchange.ca/Public/Files/BSO/Summary.aspx](http://brainxchange.ca/Public/Files/BSO/Summary.aspx).

This thesis began its investigation into the factors that led to BSO development while the BSO initiative was being implemented – therefore, data collection began before full implementation of the initiative. Throughout the data collection period, the researcher was alerted to the existence of various documents, which prompted a targeted search of publicly available sources to locate the recommended material. In addition to the sources located during the initial search noted above, the following documents were identified through a targeted search based on information made available by key informants between 2011–2013:

- four quarterly reports during the implementation of BSO that compiled the LHIN-level activity for reporting to the Coordination and Reporting Office (CRO);
- an interim evaluation report of the four early-adopter LHINs completed in 2012 by the Hay health care consulting group (Hay Group);
- sustainability plans developed by nine LHINs, which were made available in 2013 (note: all 14 LHINs now have publicly available sustainability plans).
All documents identified above are available publicly on the knowledge exchange platform known as brainXchange (http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Behavioural-Supports-Ontario/Behavioural-Supports-Ontario-Implementation.aspx).

After reading all identified documents, these were sorted into four groups based on the phases of the BSO initiative.

1. Documents related to BSO development:
   - BSO project summary
   - Older Adults Behavioural Support System
   - Policy analysis and implementation discussion paper
   - Behaviours Have Meaning

2. Documents related to BSO implementation:
   - Action plans from 14 LHINs
   - Four quarterly reports

3. Documents related to BSO evaluation:
   - Hay Group interim evaluation of early-adopter LHINs

4. Documents related to BSO sustainability:
   - Sustainability reports from nine LHINs

The list of documents for data analysis was narrowed down by referring back to the research questions. The research questions in section 1.2 are concerned with identifying the factors that led to the development of BSO, and the factors that may have influenced implementation. This thesis could not assess the evaluation process of the BSO initiative, nor assess the likelihood of sustainability of the initiative, because the data were not available for collection at the time of writing.

To reduce any duplication between the four documents related to BSO development (Group 1 in the list above), they were compared for content duplication and it was determined that the Behaviours Have Meaning document consolidated the information presented in the BSO project summary, the Older Adults Behavioural Supports System document, and the associated policy analysis and implementation discussion paper. The analysis and discussion paper was included in this group of documents related to developing the BSO initiative because the content of this document discussed possible implications and future considerations for the development of what
would become known as the BSO initiative. Because *Behaviours Have Meaning* consolidated the information found in the four documents, it was chosen as the document for analysis relating to BSO development and was coded using a framework that will be explained in section 6.2.

The two sets of documents related to BSO implementation (Group #2 above) were compared to determine if there was a need to include all 14 LHIN action plans alongside the four quarterly reports. The quarterly reports compiled the LHIN-level activity within one source. The action plans detailed what each LHIN was *going to do* and the quarterly reports summarized the reporting from each LHIN in relation to what they did to implement the action plans. It was clear after reviewing both sets of documents that the quarterly reports provided the level of detail needed for analysis, and that the content in the LHIN action plans was summarized within the quarterly reports. To reduce duplication while still responding to the research questions, the researcher concluded that LHIN action plans would not be included as a source of data. Finally, the Hay Group interim evaluation of the BSO initiative provided an analysis of the challenges that an outcome evaluation would face, with a summary of BSO activities across the early-adopter LHINs. It was not an evaluation of the implementation process or of the outcome measures for the BSO initiative; therefore, the researcher concluded that this document was more related to the implementation phase, and it was included in that analysis. For a full list of the documents included as data sources with appropriate referencing, refer to appendix A.

The above documents provide a chronology of the BSO framework and how it was designed, its guidelines for implementation, and an interim evaluation of the four early-adopter LHINs.

A note about brainXchange: All documents were originally accessed through the Alzheimer Knowledge Exchange (AKE), which was a knowledge transfer and exchange platform that operated in Ontario between 2005 and 2014. AKE amalgamated with the Canadian Dementia Resource and Knowledge Exchange (CDRAKE) in 2015 to become brainXchange. This knowledge translation and exchange hub provides access to resources, and facilitates connections between stakeholders with an interest in improving practices related to brain health.

### 6.1.2 Semi-Structured Interviews

To gather first-hand information on the factors associated with the development and implementation of the BSO initiative, the researcher conducted semi-structured interviews with
senior-level staff, who were identified as key informants using a snowball sampling method. This non-probability sampling method is often used when trying to locate hidden populations that the researcher does not know how to reach (Neuman, 2006). This method of sampling is not random in nature. Instead, the researcher identifies an initial informant who can then recommend other potential informants to the researcher. Because it relies on the identification of informants within an existing social system, the initial informant will have a strong influence over the sample. This sampling method was used because at the time the research began, implementation of the BSO initiative was still under way and identifying potential informants was challenging without seeking guidance from an initial internal source. Using key informants as a source of data provided the opportunity to gather in-depth knowledge from people directly involved in the development and implementation processes of BSO.

With this in mind, sampling began with a member of the BSO provincial steering committee who had much experience in policy and service development for people with dementia. This initial informant provided the names of staff who might be interested in participating in the project. At the end of each interview, each informant was asked if they could recommend one to three people who met the following criteria and might be interested in participating in the study.

Key informants had to meet these eligibility criteria in order to be selected:

- they are fluent in English;
- they would be available in person or over the phone for 30 minutes to one hour;
- they have worked directly with the BSO framework, whether for the Ministry of Health and Long-Term Care (MOHLTC), Health Quality Ontario (HQO), the LHINs, the Community Care Access Centres (CCACs), a community service agency, a hospital, or a long-term care home;
- they were not a client receiving care within the BSO framework;
- they were not a caregiver providing care to a person receiving care within the BSO framework.

The researcher contacted a total of 20 senior staff who were involved in the BSO initiative. Fifteen agreed to participate in the study. Thirteen met the eligibility criteria, and interviews were completed with these key informants between March 2012 and December 2013. Saturation of information was reached by the eleventh interview, but all 13 interviews were completed as
scheduled. Staff members were selected from one early-adopting LHIN and four later-adopting LHINs. With a total of five LHINs represented, these key informants cannot be considered representative of all 14 LHINs. However, the inclusion of informants from the CRO, HQO and the AKE allowed for a system-level perspective in the responses received. This aids in filling the gaps left by not having each LHIN directly represented in the sample. Below are descriptors of each informant’s role, as termed by each informant at the commencement of the interview. To protect informant anonymity, only their positions as they indicated are identified.

Table 4-1: Key Informant Interview Descriptors

<table>
<thead>
<tr>
<th>Informant number</th>
<th>Descriptor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Provincial leadership group member</td>
</tr>
<tr>
<td>2</td>
<td>BSO “Knowledgeable Care Team” working group member</td>
</tr>
<tr>
<td>3</td>
<td>Regional coordinator</td>
</tr>
<tr>
<td>4</td>
<td>Program manager</td>
</tr>
<tr>
<td>5</td>
<td>Community response behavioural team member</td>
</tr>
<tr>
<td>6</td>
<td>Health system transformation senior advisor</td>
</tr>
<tr>
<td>7</td>
<td>Quality improvement facilitator</td>
</tr>
<tr>
<td>8</td>
<td>BSO team lead</td>
</tr>
<tr>
<td>9</td>
<td>Provincial leadership group member</td>
</tr>
<tr>
<td>10</td>
<td>Knowledge exchange broker</td>
</tr>
<tr>
<td>11</td>
<td>BSO project lead</td>
</tr>
<tr>
<td>12</td>
<td>BSO provincial lead</td>
</tr>
<tr>
<td>13</td>
<td>Manager of Client Services</td>
</tr>
</tbody>
</table>

All interviews were recorded and transcribed, and notes were taken during each interview and compared with the transcriptions for accuracy. At the start of each interview, the purpose of the interview was stated, consent to participate was confirmed, and verbal consent to record the interview was obtained.

The researcher used the interview guide to seek targeted information on each informant’s perception of the BSO initiative, their involvement within it, their involvement with other government initiatives (Aging At Home [AAH] and Emergency Room/Alternate Level of Care [ER/ALC] strategies), and their personal experience with the BSO initiative during its
development and implementation. At the time the interview guide was developed in 2011, the BSO evaluation had not been confirmed, so the guide included one question seeking information on knowledge pertaining to a potential evaluation. As mentioned, the interim evaluation (Hay Group, 2012) was released shortly after interviews began in 2012. The semi-structured nature of the interviews allowed the researcher to ask questions not found in the interview guide, in order to clarify or expand on what the informant had said. This allowed for a rich collection of interview data based on each informant’s professional experience of BSO. The interview guide and consent form are attached in appendices B and C, respectively.

6.2 Data Analysis

In this thesis, the method used for analysis was inductive and deductive thematic analysis as presented by Fereday and Muir-Cochrane (2006). They use a hybrid approach to qualitative analysis, where the researcher develops a coding framework in a deductive way based on concepts from an existing theory, but also has the freedom to add codes inductively to the framework from concepts that arise from the data that are not yet included within the existing coding framework. This approach is useful when a researcher has different sources of qualitative data, as is the case in this thesis.

Using a deductive approach, where the researcher uses an existing theory or conceptual framework to develop codes, the researcher created an initial coding framework to code both interview and document data. As described in chapter 3, the conceptual framework for policy implementation as presented by Sabatier and Mazmanian (1980), as well as the theoretical perspective of causal stories (Stone, 1989) in agenda setting were used to develop initial labels for categorization. The parent codes developed with a foundation in causal stories and the policy cycle framework were 'realities of service provision/gaps', 'history' and 'agenda-setting'. The parent codes developed using Sabatier and Mazmanian’s conceptual framework of the implementation process was 'implementation' and 'perceptions of BSO'. The full coding framework is available in Appendix F.

Because these were semi-structured interviews, the coding framework was developed to allow for open coding of data that did not fit within the existing coding framework. This reduced the likelihood that the data would be constrained or limited by the existing framework, and it allowed for the identification of emerging themes.
The researcher tested this initial coding framework on two interview transcripts using NVivo10 software. To enhance the validity of the coding framework, two members of the research team coded one of the transcripts that the researcher had also coded. The secondary coders provided suggestions for refinement of existing codes, as well as the addition of new codes to the initial coding framework. The researcher reviewed the code suggestions made by the secondary coders and incorporated their suggestions by adding codes or clarifying existing codes. This process produced the refined coding framework that was used to code all 13 interviews (Appendix F).

Open codes that did not fit into the existing coding framework were coded separately, after the initial data had been entered. The six documents identified in section 6.1.1 as sources of data were then coded using the same coding framework used for the interviews. This was done because the documents contained data upon which the interview data would build. Using the same coding framework allowed the document data to be connected to the interview data by code. The open codes were then reviewed and clustered into emerging themes, refining the codes within the coding framework.

The researcher then read through the codes to review accuracy and recode as needed. The data were analyzed by applying Fereday and Muir-Cochrane’s (2006) method of connecting codes and connecting themes across codes. This process identified themes that were used to respond to the research questions.

By using two sources of information, the researcher was able to triangulate the data collected. Data collected through semi-structured interviews provided depth and contextual information for the data collected through document analysis. This convergence of information resulted in saturation of information, and no further data collection was warranted. The thesis findings are presented in chapter 7.
Chapter 7
Results

This chapter presents the thesis findings in response to the research questions, which asked:

1. What factors led to the development of the Behavioural Supports Ontario initiative?
2. What factors had an impact on how the Behavioural Supports Ontario initiative was implemented?

7 Research Findings

The themes presented in this chapter resulted from an analysis of document and key informant data and have been organized into three categories; (1) agenda setting, (2) factors influencing implementation, and (3) emergent findings. The themes are presented in table 7-1 and explained in the following subsections.

Table 7-1: Themes by Category

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
<th>Theme Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agenda Setting</td>
<td>Problem recognition and policy goals</td>
<td>The recognition of a problem in service delivery and/or system performance, and the connection to policy goal development.</td>
</tr>
<tr>
<td></td>
<td>Developing a solution</td>
<td>The formulation of solutions to the identified problem(s).</td>
</tr>
<tr>
<td>Factors Influencing Implementation</td>
<td>Government funding availability</td>
<td>The amount of funding available from the Ontario government.</td>
</tr>
<tr>
<td></td>
<td>Implementation fatigue</td>
<td>Feeling of fatigue due to implementing many initiatives simultaneously.</td>
</tr>
<tr>
<td></td>
<td>Staff turnover and knowledge discontinuity</td>
<td>Loss of knowledge on how to provide appropriate dementia care within an organization due to staff turnover.</td>
</tr>
<tr>
<td></td>
<td>Risk of policy conversion</td>
<td>Movement away from original implementation goals.</td>
</tr>
<tr>
<td>Emergent Findings</td>
<td>Comparing development and implementation approaches</td>
<td>Comparing the development and implementation approaches of various related policies.</td>
</tr>
<tr>
<td></td>
<td>Evaluation challenges</td>
<td>Challenges experienced when conducting an evaluation of BSO.</td>
</tr>
<tr>
<td></td>
<td>Perceptions of PSWs</td>
<td>How others perceive the role of PSWs in the provision of dementia care.</td>
</tr>
</tbody>
</table>

7.1 Agenda Setting

Agenda setting is the process by which a topic or issue is understood to be important enough to garner attention from government (Howlett, Ramesh & Perl, 2009). The challenge of providing quality care to people who exhibit responsive behaviours came to the attention of the Ontario government after a series of events that was catalyzed by the Casa Verde incident.
In 2001, a recently admitted resident who had a history of aggression bludgeoned two other residents to death at the Casa Verde nursing home in Toronto, Ontario. Public outcry resulted in an investigation by the coroner’s office. When the final report was released in 2005, 62 of 85 recommendations were directed at the MOHLTC in an effort to reduce the likelihood an incident like this would happen again (Office of the Chief Coroner, 2005).

The most salient recommendations from the Coroner's report related to the development of the BSO initiative stress the need for a framework of care that recognizes the unique needs of this population, that requires UFIRST/P.I.E.C.E.S, or equivalent, training for all front-line workers, and provides specialized facilities where people with responsive behaviours can access appropriate care while maintaining the safety of others (Office of the Chief Coroner, 2005). A list of these recommendations can be found in appendix G.

The costs of not doing anything were now linked to the death of 2 people, and were deemed too high in the eyes of the public, who demanded an inquest. Though there were likely other cases of aggression leading to injury and death, the Casa Verde inquest established the sentiment that something must be done. In line with the concept of a causal story, the recommendations that resulted from the inquest set out a path that the government could take to remedy the problem of responsive behaviours in long-term care homes. In addition, growth in the number of people with the potential to exhibit responsive behaviours added pressure for action on this issue.

As the numbers of individuals with dementia, complex mental health conditions and cognitive impairments increase, so will the incidence of responsive behaviours associated with these conditions. Older adults with cognitive impairments who are exhibiting challenging behaviour may be a relatively small group in relation to the total seniors’ population, however, effectively meeting the complex needs of this group has a significant impact on the health care system. This will only further increase as the oldest adults demographic (age 85+) continues to grow along with the disproportionate increase in dementia, depression and other mental illnesses, and substance abuse disorders (Ontario BSS Project Team, 2010, p. 8).

One of the factors to consider in the implementation process, according to Sabatier and Mazmanian (1980), is having an adequate causal theory as to how to achieve the desired policy objective. The causal theory underlying the BSO initiative is that quality care for people exhibiting responsive behaviours is achievable if services across systems are coordinated, service delivery is integrated, and care providers are knowledgeable and have the capacity to provide such care (Ontario BSS Project Team, 2010).
This causal theory is the basis for the activity that followed the Casa Verde incident. In 2007, the MOHLTC drafted a report titled *Building a Better System: Caring for Older Individuals with Aggressive Behaviours in Long-Term Care* in response to the coroner’s inquest. This report examined the components and the approach required to establish a LHIN-based system of care for older adults with responsive behaviours (Ontario Ministry of Health and Long-Term Care, 2007b). The government recognized that the current system was not providing the right care, and that there was a need to “build a better system” of care for this group of people.

*It was really an approved process by the Ministry, that this is the way that we would move it forward and the strategy for implementing the framework was also developed and approved by the particular deputy minister collaborating with his or her colleagues* (Key Informant 9).

This report laid the groundwork for the Behavioural Supports Ontario initiative.

### 7.1.1 Problem Recognition and Policy Goals

The process of recognizing problems was an important step toward the development and implementation of the BSO initiative. Key informants identified areas for improvement that could be considered policy goals for the government’s response. These problems included the use of emergency departments and the need for an alternate level of care, staffing issues related to deficits in training and knowledge of responsive behaviours, and challenges with coordinating care across sectors and not using established best practices. These sub-themes are presented below from the perspectives of key informants.

#### 7.1.1.1 Emergency Departments and Alternate Level of Care Days

*Behaviours Have Meaning* explains how community caregivers may turn to emergency care when in crisis. However, a person admitted to the hospital through the emergency department may only be discharged from acute care if an appropriate alternate level of care can be secured for them; they might require long-term care, but it may not be immediately available.

Caregivers often find they no longer can cope in the community and may go in crisis to the nearest emergency department. This can result in patients waiting in acute care beds for long-term care placement for unacceptably long periods. Individuals admitted through the emergency department account for 73% of alternative level of care (ALC) bed days in Canada (Ontario BSS Project Team, 2010, p. 13).
“ALC bed days” refers to a patient occupying an acute care bed when they no longer need it because an alternate level of care isn’t available. The BSO target population (people with responsive behaviours due to dementia, mental illness, or neurological conditions) was identified in the interim evaluation as having longer lengths of stay when designated as needing acute care as well as an alternate level of care.

The average acute care length of stay for the BSO Target Population is 20.86 days, almost three times as long as the average length of stay for the non-BSO Target Population. The average length of stay as “Alternate Level of Care” is 8.54 days for the BSO Target Population, compared to only 1.04 days for the non-BSO Target Population (Hay Group, 2012, p. 37).

Waiting for another level of care was recognized as a problem across the province. In general, the length of stay in an acute care setting for people with dementia was noted to be comparably higher than those without a dementia diagnosis.

ALC patients in Canada were more than twice as likely to have a co-morbid condition, and dementia as a main or co-morbid diagnosis accounted for almost one quarter of ALC hospitalizations and more than one third of ALC days. Patients with dementia as a main diagnosis had a median ALC length of stay of 23 days compared with 10 days for ALC patients overall. […] A July 2010 survey of acute care hospitals in Ontario reported that ALC patients occupied 17% of all acute care beds in the province and half of these were waiting for long-term care. In a recent analysis of alternate level of care patients waiting for long-term care in Ontario over 53% had moderate to severe cognitive impairment and over 19% had exhibited behaviours such as wandering, verbal abuse, physical abuse, socially inappropriate behaviour and resisting care (Ontario BSS Project Team, 2010, pg. 12).

Key Informant 6 indicated that the increased length of hospital stay for the BSO target population may be linked to the inability of the receiving long-term care home to provide the appropriate care to the person exhibiting responsive behaviours.

I don’t want to say that long-term care wouldn’t take them, but sometimes they get stuck in the hospital because when there are severe behaviours, long-term care homes just aren’t equipped to deal with that, so sometimes they end up, you know, in inappropriate places within the system (Key Informant 6).

Similarly, Key Informant 3 spoke of the use of emergency departments by long-term care homes when they can no longer safely handle the patient, but then once the patient has been discharged back to the home, the same situation awaits, because the home doesn’t have the resources to support the person exhibiting responsive behaviours.
So we know that, as an example, oftentimes long-term care homes will send someone to ER because they feel they need further medical investigation or they’re just not sure how to meet the responsive behaviour. And the ER and potentially the hospital will do what they can and the resident may then be appropriate for discharge and the home may be very tentative in accepting them back because previously they did not feel they had the resources (Key Informant 3).

7.1.1.2 Uncoordinated Care

Care coordination involves care professionals working with patients (and with each other) to ensure that the patient’s health needs are being met and that the right worker is delivering the right care at the right time (Traver, 2013). This deliberate process organizes care activities across settings and sectors of the health system, and includes the sharing of information among all participants in a person’s care (Agency for Healthcare Research and Quality, 2015). Poor coordination of care and poor integration across service providers and across sectors within the health system was recognized as a problem in both informant and document data for the BSO target population.

Whereas before, you know, one agency would treat you here, you’d go to the next and there was no continuation (Key Informant 3).

What was the problem was that they were not necessarily integrated sufficiently with one another to enable transitions to occur smoothly for people with dementia and families. The skills of the workers in those service sites were not necessarily adequate ... to the task. And families were not adequately supported in terms of coordination (Key Informant 1).

Each one of the sectors is trying to find ways to address the issues, but their approaches tend to be fragmented and sector focused. The system has not reached a point where the care is integrated across all sectors and this vulnerable population cannot manage with anything less (Ontario BSS Project Team, 2010, pg. 10).

...we know that the skill base of providers and others, and the richness of knowledge of people with experience to be actively involved in his or her care are not good enough. And we know that the health care system stinks because it’s fragmented, disconnected, and we work in silos. We don’t really work – as far as what happens to the person – at looking at a continuum of care (Key Informant 9).

Over all, best practices in dementia care were not being enacted within the health system. As summarized in Behaviours Have Meaning, best practices included the “integration of multiple disciplines, integration with primary health care, co-location of services, supportive systems, funding arrangements, clinical relationships, consumer centeredness, patient education, and
provider skills and education” (Ontario BSS Project Team, 2010, p. 13). Key informants concurred that problems existed related to integration, education, and coordination of care.

7.1.1.3 Staffing Issues

Key informants highlighted that staff who currently provide service and supports to people with dementia often do not have adequate training, knowledge or skills to effectively interpret and respond to behaviours that may arise. Across the system, a deficit in staff skill sets presented a major challenge to be addressed by the policy initiative being considered for development.

[Family] Caregivers with lived experience are telling us that we need to make some important changes to address their needs. They recommend that the system teach health care workers more about the responsive behaviours associated with dementia and note that health care workers are often not aware of how to manage or prevent behaviours (Ontario BSS Project Team, 2010, p. 10).

So, you have people that are working out there that are coming in contact with persons with some behavioural responses, but those tools and ways to sort of mitigate that were not always there (Key Informant 10).

In our health system, our health providers have a significant skill-building challenge in front of them: how to do knowledge exchange effectively as well as quality improvement (Key Informant 9).

There was also the issue of simply not having enough time to dedicate the level of attention required for quality care provision. Demand for service was perceived to be higher than what current staff levels were able to effectively support. Key Informant 3 gives an example of how following up with a referral can slip through the cracks.

So, for example, if a referral is made and they are not hearing back from that referral source or if they decline initially, we know that sometimes it takes a number of engagements with a caregiver to agree to some form of service or support. And given the level of demand on a number of agencies, oftentimes the person is just filed away and follow-up isn’t conducted (Key Informant 3).

7.1.2 Developing a Solution

The aforementioned issues with emergency department use, ALC days, uncoordinated care, and staffing issues related to training and lack of time to implement best practices are not experiences unique to this population, but have been common issues faced by a variety of sub-populations across Ontario’s health and social care systems. The discussion in chapter 6 also identified these
problems as policy goals and the targeted interventions to lessen them in three preceding Ontario policies. In developing the BSO initiative, stakeholders had to identify methods of overcoming the misuse of emergency departments, ALC days, uncoordinated care, and staffing issues in a way that addressed the unique challenges that responsive behaviours presented – which differed from the approaches used in the preceding Alzheimer, AAH and ER/ALC strategies. BSO was developed with an understanding of these preceding policies and their effects, but the stakeholders involved determined that the specific BSO population needed a targeted approach.

*The major role [of BSO] was to do three things for the population. It was to focus on people at risk who also showed responsive behaviours that were either associated with cognitive problems like dementia, mental health and addictions and neurological disorders. And the major process was to shift the system of health care delivery and change direction so that there would be better health and better care and better value for the [BSO] population (Key Informant 9).*

Stakeholders acknowledged that although the available services formed a good foundation, they needed to be coordinated in a way that was more client/patient-centred in order to better support people with dementia who exhibited responsive behaviours.

*Before, it was very provider-centric. So, it was ‘what does a provider do for you?’ Whereas this [BSO] has been a much different approach in that we’re listening to – not that we didn’t before, but we’re listening to what the needs are and then addressing those needs rather than saying, well, this provider can do this and can do that; it’s more client driven, which is, in my opinion, the much better way to go (Key Informant 7).*

As Key Informant 1 put it,

*It was our thinking that the infrastructure was in place, there was enough service out there, enough service points. It was that people didn’t know what they were doing necessarily or didn’t know what each other was doing and therefore were unable to help either clients or families. So that was kind of our thinking. What we needed to do was to improve the skill set, improve the connection between services, improve the way that services were coordinated (Key Informant 1).*

BSO was designed by stakeholders who had an interest in improving the care provided to persons with responsive behaviours. These stakeholders included:

- the Alzheimer Society of Ontario, a registered charity;
- the North-Simcoe Muskoka (NSM) LHIN. The boundaries of this area encompass the District of Muskoka, most of the County of Simcoe, and a portion of Grey County in Central Ontario;
the Communities of Practice from online knowledge exchange platforms – specifically, the Seniors Health Research Transfer Network Community of Practice (SHRTN CoP), associated with the Alzheimer Knowledge Exchange (AKE), which is focused on seniors with mental illness, addictions, and behavioural issues.

In January 2009, these stakeholders identified an opportunity to bring together organizations that were developing, or were planning to develop, organization-specific behavioural support programs (Ontario Behavioural Support System Project Team, 2010). A series of knowledge exchange sessions were conducted where people participated in webinars and collaborative discussion groups online to identify issues and discuss potential solutions. During the sessions, organizations and health professionals provided guidance on what would later become the basis for the BSO initiative. In April 2009, early leaders in this area convened in Toronto to discuss and formulate an integrated Behavioural Support Systems (BSS) Project plan. These discussions identified that whatever initiative was developed, there would need to be strong provincial leadership and a shared model for BSO across the 14 LHINs in order to overcome the varied nature of service provision across LHIN jurisdictions. After this meeting, a working group was established to oversee outcomes from the session. This group included representatives from the Alzheimer Society of Ontario, hospital, community and long-term care groups, as well as health care professionals like geriatric psychiatrists and nurses (Ontario Behavioural Support System Project Team, 2010).

The MOHLTC announced one-time funding to the NSM LHIN under a BSS long-term care initiative that later became known as BSO. This information was made public in January 2010, initiating the first phase of BSO, known at the time as the Ontario Behavioural Support System Project. This first phase was to develop a “Framework for Care for a Service Redesign Initiative” across the LHINs that would mitigate the strain on and improve outcomes for persons with responsive behaviours, families, health providers, and the health care system (Ontario Behavioural Support System Project Team, 2010). This report incorporated input from family caregivers and clinicians through 11 cross-sector meetings that occurred across the province. The information gathered through these meetings was combined with evidence from the literature to inform the development of the BSO initiative.
Three different kinds of evidence inform this key work: lived experience, practice-based information and research. Throughout this first phase, the Ontario BSS Project engaged and integrated:

- Advice and insight from approximately 100 caregivers of older persons with responsive behaviours
- Outcomes from regional forums hosted by the Seniors Health Research Transfer Network’s Mental Health Community of Practice,
- Comments and suggested revisions gained from the volunteer members of the Virtual Advisory Panel [knowledge exchange session]
- Feedback from key informant interviews and opinion leaders from targeted sectors
- A literature review of relevant research-based literature and resources (Ontario BSS Project Team, 2010).

Key informants for this thesis noted that the involvement of front-line staff in the development process of the BSO initiative, through consultations and stakeholder engagement activities, increased stakeholder buy-in from service provider organizations when it came time to implement the BSO initiative.

...front-line service providers had an opportunity to participate in designing the change process and therefore became a little bit more engaged (Key Informant 1).

So, yeah, I think our community was ready. I think there was an awareness, and I think we were in a position that we could deliver it fairly strategically and roll it out. I think if ... we didn’t have the opportunity that they gave us to, you know, shift that long-term care model [i.e., embedded versus mobile model for BSO support teams], I think it would have been much harder to roll out because we wouldn’t have had buy-in from our long-term care homes. And we had true buy-in. So it was good (Key Informant 4).

Overall, key informants noted that the BSO initiative was developed as a solution to the problems discussed earlier in the chapter. In 2011, the MOHLTC launched phase two of BSO, to redesign the system of care for seniors across Ontario, as well as for their families and caregivers who live with their responsive behaviours associated with dementia, mental illness, addictions, and other neurological conditions (Gutmanis et al., 2015). BSO was considered a comprehensive system redesign that breaks down barriers, encourages collaborative work, shares knowledge and fosters partnerships among local, regional, and provincial agencies (Gutmanis et al., 2015).
7.2 Factors Influencing Implementation

The second thesis research question asks: “What factors had an impact on how the Behavioural Supports Ontario initiative was implemented?” At the time of data collection, the BSO initiative was in the midst of implementation. Key informants spoke about events or circumstances that influenced how the BSO initiative was being implemented at the time of interview. These factors were grouped into four themes: government funding availability for implementation, implementation fatigue among care providers, staff turnover and knowledge discontinuity, and the risk of policy conversion throughout implementation. These themes are presented in the following subsections.

7.2.1 Government Funding Availability

The BSO initiative required government support and funding for full implementation. Key informants provided insight into decisions made by the Ontario government, through the MOHLTC, to fund the BSO initiative, including the extent to which the government would fund BSO on an ongoing basis.

The initial request for funding the BSO initiative was $4 million. This would provide initial funding for the establishment of the BSO framework, including the use of the AKE as a way to collaborate and connect across existing sector and geographic silos while the framework was developed. The goal was to use the $4 million to develop the basic technological infrastructure, identify four LHINs that would act as early adopters of the BSO initiative, and to begin connecting with the health service providers that would be involved with the full implementation of the BSO initiative. The stakeholders presented in section 7.1.2 recognized that in order for the BSO initiative to be implemented across all 14 LHINs, additional funding would be needed.

Key informants shared their perspectives on the development of the decision to increase BSO funding from the original $4 million.

Initially the proposal was that early-adopter LHINs would implement BSO for approximately a year and then it would spread throughout the province. What actually transpired was the early-adopter LHINs were agreed upon, but soon after that it went from something like a budget of $4 million or something for the four early-adopter LHINs to $40 million across the province in approximately two months. So the goal of training staff through BSO went from 70 people to 700 people.
The other thing that often happens is the convergence of pain, policy, consumer push, and political expediency. An election was coming up and it was very important that these promises be fulfilled by the government at that juncture, so I think that accelerated it from a year to two months (Key Informant 1).

An upcoming election in 2014 supported the accelerated pace of implementation across all 14 LHINs, as the MOHLTC recognized they had made previous commitments to improving long-term care services and increasing nursing supports. This is because governments want to show they have accomplished their goals prior to entering the next election. The BSO framework was well-positioned to be expanded given its stage of development and targets for improvement, so additional funding was committed to facilitate this expansion with a focus on long-term care training and nursing hires.

And the reason for that change was that there was a political conversion and it was connecting the dots across the various ministries that identified – there was an initiative and a promise by the Ministry that they would increase the number of nurses in the province. There was also an existing promise that they would enhance the long-term care sector with more support. And so you had the nursing secretariat, you had the long-term care part of the Ministry, and then this initiative to innovate (Key Informant 9).

Within the Ministry there was somebody who pulled the gaps together and identified – Minister, you can accomplish all of these things if you roll out the BSO project. So the added funding actually was for nurses and for long-term care (Key Informant 1).

This resulted in an additional $40 million being committed to the implementation of the BSO initiative, for a total of $44 million in initial BSO funding. This political decision had an impact on the decision to implement BSO, and the direction of who received funding and for what purpose.

The findings related to the funding of the BSO initiative give a conflicting impression of BSO funding sustainability. As presented above, the original funding for the BSO initiative was connected to staff hiring and training priorities within the long-term care sector. The opportunity that opened increased the amount of initial government funding for the initiative from $4 million to $44 million as implementation began in the remaining ten LHINs in phase three. Eight key informants shared that they thought funding could be a barrier to the success of BSO: although it

\[1\] NOTE: The interviews for this thesis took place between 2011–2012, so the total amount noted is only for the period of 2010–2012. The amount invested by the Government of Ontario into the BSO initiative totaled $59 million by the end of 2013 (Ontario Ministry of Health and Long-Term Care, 2015).
had received some funding, the ongoing nature of this initiative would require continuous and reliable funding. As Key Informant 2 said,

*I’m not sure where the funding starts and stops but I think March 31st ... that’s the problem with a lot of the initiatives, they get rolling out, there’s funding to support a lead and a person to help to roll it out, and then the funding ends. And everyone’s supposed to know what’s going on and keep it going while they’re still operating their services and programs* (Key Informant 2).

Likewise, Key Informant 6 responded that funding was a barrier because the money allocated for the BSO initiative was not operational money, and the informant noted this in relation to the use of mobile teams as an intervention within the BSO framework of care.

*...funding is always a barrier. Even though the BSO came with money, it didn’t come with operational money. So, as an example, you know, we brought together a bunch of mobile teams. Well, they don’t have the budget to travel. So ... things like that are just ... somebody needs to come up with the money, but then, you know, everybody is protective about their budgets, so ... it always comes down to money* (Key Informant 6).

In contrast, Key Informant 9 was very confident that the funding for the BSO initiative, which at the time of the interview was $43 million, was annualized and ongoing. There is mention of a ten-year timeline, but the informant assured me that the funding was to be considered permanent within the health budget:

Key Informant 9: *Well, first of all, I think most people need to step back and step up. There is $43 million annualized funding [split across all LHINs].*

Interviewer: Oh, it’s annualized. Okay.

Key Informant 9: *It goes on forever.*

Interviewer: Oh, I did not know that. I thought it was a one-time thing.

Key Informant 9: *Oh. People always love to think that’s the case, but the thing is, if that $43 million is not focused on a catalyst, we’ll end up going back into sort of the old ways of doing things.*

Interviewer: So it’ll be targeted to services if we don’t –

Key Informant 9: *Right.*

Interviewer: Okay. And just to clarify for myself: so, the $43 million that’s annualized, was that annualized right away or is that something that was just recently announced moving forward?

Key Informant 9: *That was annualized right away. Everybody said it was only a ten-year strategy and nothing was annualized; that’s not true, either.*
Funding for BSO continued after the initial infusion of resources, but the researcher was unable to determine for certain whether funding for the BSO initiative was annualized and ongoing from the available data. Further inquiry is necessary to determine whether the BSO initiative receives ongoing and annualized funding from the MOHLTC, and, if so, how much this funding is each year.

### 7.2.2 Implementation Fatigue

A second factor that had an impact on the implementation of the BSO initiative was the extent to which direct service providers and front-line staff were able to carry out implementation activities specific to their sector or role within the framework. The focus on health system transformation in Ontario has resulted in a push for change within health care that has had an effect on front-line providers. The ability of front-line providers to implement this or any other initiative will be influenced by workplace realities like increasing demand for services, limited resources, and overlapping priorities. One consequence may be termed “implementation fatigue,” and the key informants suggested this was a major factor influencing the implementation of the BSO initiative.

One informant, who worked for a service provider organization, explained how the pace of change had been fast, with multiple, simultaneous initiatives occurring that had both complementary and competing priorities. Their response indicates that they were experiencing a certain level of “implementation fatigue,” as a provider attempting to balance providing existing services with improving other services concurrently.

> It’s really difficult, as a service provider, to be on all these committees, and keep everything running smoothly and keep the communication lines running smoothly when you’re trying to operate your own programs. And there’s a lot of expectation that once something’s started that it will just run on its own. And then, you know, when things fail, they wonder why ... our sectors have been dealing with change, massive amounts of change in a short period of time with many, many initiatives all at once. And it’s from one to the next, to the next. And then overlapping two or three at a time. And you’re trying to keep up on all of it. So, you know, as good as BSO has been through this whole process, it’s one of many initiatives. So it’s just sometimes you’re overwhelmed with information and you’re getting the information but you’re getting information from three different spaces for three different initiatives.

> So, there’s a lot of overwhelm [being felt by providers]. So, I think that any of the negatives are a response to the [feelings of] overwhelm that the sector’s been under. And
all of that is a result of multiple initiatives being thrown at us with very short deadlines (Key Informant 2).

7.2.3 Staff Turnover and Knowledge Discontinuity

The third factor that had an impact on the implementation of the BSO initiative was the extent to which the additional knowledge being inserted into care provision would remain in the organizations. The retention of staff who provide direct service to people with dementia and other conditions that involve responsive behaviours is an ongoing challenge. PSWs provide the majority of direct care to people in long-term care homes and the community, where the majority of people with dementia live. These PSWs work with registered practical nurses and registered nurses to provide direct care. The informants recognized that the nature of employment in their sectors meant that there was regular turnover of staff, which challenged the continuity of knowledge within organizations.

I think we’re going to be in a bit of a situation with, you know, having the proper skilled labour in health care. Labour shortages may play a role in it down the road.[...] If there’s turnover ... that makes it difficult because now you’re having to retrain people ... and you lose that organizational knowledge (Key Informant 7).

I think we need to ensure continuity so if there’s staff turnover ... there’s a continuity of the presence of the added expertise. Like, that expertise can diminish as people change positions, et cetera. The other thing is that there should be an insured investment in education every year (Key Informant 10).

Within the data there was some evidence to support the notion that the rate of turnover for these direct-care providers is related to high demand for skilled workers in this field.

So there’s that risk piece. And ... the barrier I see is that we just don’t have enough PSWs and enough nurses in the field.... It’s just a competitive field (Key Informant 4).

One of the major deliverables of the BSO initiative was to train over 700 front-line staff in alternative approaches to addressing responsive behaviours. With high turnover rates, however, the value added by training staff would be subsequently lost each time a staff member was replaced; any new hires would need retraining to fill the knowledge gap.

7.2.4 Risk of Policy Conversion

The fourth factor in implementing the BSO initiative was the degree to which BSO could operate as a framework for care, rather than simply being perceived as an additional funding source for
direct-care provision. Because BSO is not actually a service, but an initiative that provides a framework and tools to support changes to service provision, there is a risk that stakeholder perceptions may shift toward viewing BSO as “just another funding stream” (Key Informant 1). Key Informant 4 identified that when resources are tight and there are not enough staff to provide direct service, there is a risk that resources dedicated to BSO activities may shift to other areas:

"But there is that risk which can ... if you don’t have enough health human resources, there’s a risk of if somebody needs attention on another floor [of the long-term care home] and you don’t have enough staff, the person who’s delivering the BSO [intervention] may have to be pulled (Key Informant 4)."

The services provided through the infusion of funding tied to BSO activities can become the focus for administrators, and stakeholders can lose sight of the purpose of BSO as a whole. One informant identified the need for leadership in order to maintain an overall focus on BSO as an ongoing, system-wide redesign activity rather than simply a source for funding more staff.

"Well, I think there needs to be what I would call a leadership message that says that this is important, this is an important issue that should be attended to. I think there needs to be confirmation of resources around skill development and knowledge translation and exchange. There needs to be some structures in place to continue to link the field together, otherwise there’s a natural tendency for people to go away and do their own thing. And I’m not being critical of that, that’s just human nature (Key Informant 1)."

Building on this, Key Informant 9 explains,

"...the BSO is a catalyst for change, it’s not a service. It’s to support the system of care and not to support the silo of one area or the other. And it’s to promote and support [a] person-centred approach and care and skill-building [across long-term care, acute care and community/home care]. We have done some work [to continue having a provincial coordinating body after initial implementation], but there’s a drift occurring at this point. Drift [in] understanding what BSO is all about, drift in going back to the old ways of doing things, drift in terms of thinking about this as a service, and drift in not focusing in on the support systems. If we do not continue, in this province, to have a framework and a strategy that continues to bring people back to the “why” and the “what” of BSO, we will have another service, but we will fail the population, we will fail the investment of money that has gone. We will not leverage other resources, and we will lose the enthusiasm and innovation and partnerships that have occurred (Key Informant 9)."

These informants are describing the risk of policy conversion; through conversion, the essence of BSO and the purpose of this initiative will be lost over time. Their concerns highlight the risk involved in implementing a framework in a domain where funding pressures are high.
7.3 Emergent Findings

Three themes emerged in the data that did not directly identify factors leading to development or influencing implementation, but which were nevertheless important to report in order to garner a deeper understanding of the BSO initiative. These involve the extent to which the approach to implementing BSO differed from the preceding Aging At Home strategy, how the process of evaluation factored into the development of the BSO initiative, and how the initiative changed the way PSWs were perceived by other health service workers and administrators. These three emergent themes are presented in the following subsections.

7.3.1 Comparing Approaches to Development and Implementation

Throughout the interviews, key informants made comparisons between the BSO initiative and the Aging At Home strategy. The AAH strategy targeted additional resources toward seniors in the community, of which a small population would have included people with dementia or other conditions associated with increased rates of responsive behaviours. Section 6.2 provided an overview of the AAH strategy, while section 6.3 outlined the BSO initiative. The key informants identified ways the BSO initiative differed from the AAH strategy in how each was developed and implemented. Key Informant 1 noted that the investments available in the AAH strategy had established roles and supports that were still available, but needed to be integrated better to serve the BSO target population.

*We had done an analysis of the investments from Aging at Home and while there were a lot of investments made in direct service to people there was very little investment made in integrating those services or connecting them one with the other or in building the skills of the staff who were required* (Key Informant 1).

Several informants asserted that the development of BSO differed from the AAH strategy in the general direction in which policy was developed. Rather than the top-down, provincial approach seen in the AAH strategy, the BSO initiative was seen as a more collaborative and bottom-up policy development process.

*I think of the things that have always been used as an approach – to develop something provincially, a policy, a service initiative, and then that service initiative is rolled out in the province and given to the various regional and local districts to implement. So, for example, when ... it was the initiative to try to improve services for seniors in the community with mental health and addictions [the Aging At Home strategy], the approach – both the service policy and implementation – was combined and developed in*
Queen’s Park [Ontario’s Legislature] and then identified as something that needs to be rolled out at the local level. It was more of a top-level kind of process (Key Informant 9).

Another way BSO differed from the AAH strategy was in the way direct-service provider organizations, key front-line providers, and family caregivers were involved in the development of the initiative from the very beginning, through roundtables, workshops, and brainstorming sessions. Key Informant 9 outlined how the involvement of these stakeholders differed in the BSO’s approach as compared to those past.

Those [prior] strategies were usually defined by a small group of experts based on a literature search. Behavioural Supports Ontario was a bit different in its development, really was a bit different in that it’s not sort of an evidence-based approach [based in the literature], but an evidence-informed approach [informed by the literature and successful existing practices]. There were quite significant activities occurring to try to identify the best practices that were out there, what were the issues, what would be the best approach to take from a research and literature point of view. But there was also quite a significant effort to bring practices together. So there [were] about 400 people across the province [who] were engaged in the practice field servicing this population. To identify from them ... the issues, what needs to be changed, what might work to change what happened [in care]. So, there was input from their perspective. And then the third part was from lived experience [family caregivers]. So there was a significant focus in regards to understanding and appreciating – asking people in the families, what were the issues for them? And it was a convergence of those three databases of evidence that formulated a framework for the province (Key Informant 9).

A defining difference between the AAH strategy and the BSO initiative involved the level of sharing and communication between the LHINs. When compared to the AAH strategy, BSO facilitated collaboration across LHIN jurisdictions so that the implementation was less siloed than what had been experienced by the nine informants who had also worked within the AAH strategy.

The difference in the BSO strategy is that we worked very closely with four LHINs to develop not necessarily a common approach but to share information about the approaches being adopted and to identify opportunities for LHINs to work with one another and to share knowledge either directly as a LHIN or indirectly through the field. And then that, starting with that four [the early adopters], it built out to the other ten. That was different than the Aging At Home strategy – that was very much conducted in isolation by each LHIN. So, that’s the first thing, I think, was getting the LHINs to work together (Key Informant 3).

So, I think, you know, Aging At Home was great at the local level and working in partnership with our partners and identifying the need. But I also found great value and I
learned a lot by linking with the other BSO leads and being part of the [AKE] collaboratives and having an opportunity for knowledge exchange (Key Informant 11).

Key Informant 1 elaborates on how collaboration happened across LHINs, using an approach that identified the four early-adopter LHINs, which were to provide guidance to the other ten LHINs once they began implementation. This was supported by Health Quality Ontario, which advises on provincial health care quality and assisted with LHIN engagement in the BSO initiative.

*Health Quality Ontario helped each of the LHINs to design the intervention plan [action plan], using value stream mapping to develop the plan for each LHIN, and then we had opportunities to share those plans. So that was a very unique contribution that wasn’t available to LHINs in the Aging At Home strategy (Key Informant 1).*

During the interview, Key Informant 3 concurred that this cross-LHIN sharing was not available from their professional experience with implementing the AAH strategy.

**Interviewer:** So, it sounds like the opportunity to seek guidance from other LHINs has actually been helpful in approaching your clients. Is that something that happened before or is that something that you’ve seen before?

**Key Informant 3:** Generally not. The general perspective that I had prior to BSO was that service providers would do as much as they could within their own agency and they might pull in one other agency, you know, that they’re familiar with, but that would be the extent of it. It would sort of be that we’ve done the best we can, we’ll refer you on and have a nice day. This [BSO] really puts together an accountability component and a real collaborative feel to case management and looking at best options for the clients (Key Informant 3).

Similarly, Key Informant 8 agreed that the approach in designing the BSO initiative differed from the AAH strategy in that there was an expectation that LHINs would communicate across geographic boundaries. This informant highlights how this approach to implementation resulted in challenging experiences, but that from their perspective it was worth it in order to identify areas for improvement.

*...I think the most striking difference was the connection across LHINs. And so from a policy perspective, that made it ... it makes it much more likely that there will be some change that comes out of it. It was the project infrastructure that allowed and in fact expected the LHINs to communicate about what they were doing and to share their ideas and to share their issues. And so, quite frankly, sometimes [there were] some pretty tough conversations, but wonderful because it allowed us to start to identify, you know ... some of the gaps from a policy perspective. You know, are there some things that we could be helping with that should be supported on a bigger-picture basis? So, I think that was the*
big difference between this one [BSO] and perhaps other strategies that were seen only on a local level (Key Informant 8).

This informant connected the benefits of cross-LHIN communication that supported province-wide action to the ability of LHINs to plan locally, based on the needs and resources within their communities. By doing this, Key Informant 8 identified one of the defining characteristics of the BSO initiative: valuing the local context while recognizing the need for provincial oversight.

The flip side of that is also true, though, where there was that ability still for there to be the local contextualization of any change and that is equally important. So, it’s important to communicate across the province but it’s also important to recognize that it can’t be only one solution. It was about rapid change, it was about multiple solutions being put in place at the same time. So, that was an important piece as well (Key Informant 8).

This was supported by Key Informant 9:

So, the BSO really just identified a framework that set down a set of principles, identified the population, and identified three pillars for change that needed to be considered when moving forward […] the provincial oversight [was] to ensure that that framework was being implemented. It might not be implemented the same in every area, but the idea was that you could be consistent with common goals and common vision and approach that was aligned with the BSO framework. So, that’s a bit different than other initiatives where there tended to be much more of a cookie-cutter approach – such as, “we’re going to develop a nurse practitioner service program, here’s what it looks like. This is what you need to do” (Key Informant 9).

The expectation that LHINs would evaluate their local needs, develop local solutions, and then share plans and compare against a provincial framework for operability and accountability was elaborated on by Key Informant 8:

We know very clearly that … context matters. So, when you’re working on this – and there was a decision early on in the BSO initiative that we weren’t looking for a standardized approach across the province. Where it made sense, absolutely, we wanted people to share, and absolutely, we would ideally like people to be approaching things the same way, but there was recognition that the existing services across the province are different and the communities are different. So, what works, for example, in downtown Toronto isn’t going to work in a remote community in northern Ontario. And so, we wanted to be sure that whatever the changes were being put in place, that they would make sense [in] a local context (Key Informant 8).

Finally, one key informant perceived the BSO initiative to be taking what was established in the AAH strategy to the next level, as if the AAH strategy had provided a foundation for BSO to be built upon.
I would say that the Aging At Home for us was unique in that, as I mentioned, the LHIN called us together for year three [of AAH] and said, you know, this [behavioural supports] is a problem. This is a gap locally.

I think what I really liked about BSO is that it brought it [i.e., what was started through AAH] up to the next level, the provincial level. So BSO’s able to link with other LHINs. And we had a provincial resource team that was able to give us some really good direction and advice.

So I think, you know, Aging At Home was great at the local level and working in partnership with our partners and identifying the need. But I also found great value and I learned a lot by linking with the other BSO leads [in other LHINs] and being part of the LHIN collaboratives [through the AKE] and having an opportunity for knowledge exchange (Key Informant 11).

7.3.2 Evaluation Challenges

The second emergent theme was labelled “evaluation challenges” due to the complexity of identifying the BSO target population and changes in the timeframe for implementation. Evaluating the impact of the BSO initiative was clearly indicated as a priority in Behaviours Have Meaning. There were two major approaches used to evaluate BSO’s impact. First was the quarterly reporting of indicators by the LHINs to the CRO during implementation:

So, each of the LHINs reported what was happening regionally: how the funds were allocated; how many people were being trained; what goals did they have in regards to behavioural supports; and then how were they going to implement them? So, getting all the numbers, like the data. But then also they had a lot of stories that they would filter back up provincially. So, the success stories or even some of the barriers that they faced, you know, actually hearing from the health service providers themselves ... all of those things were gathered quarterly, and distributed on a provincial level (Key Informant 10).

The second method of evaluation, conducted by the Hay Group, focused on assessing the impact of the BSO initiative on the four early-adopter LHINs. As implementation continued, the ability to identify the target population of people with responsive behaviours within existing administrative databases proved challenging and influenced the direction of evaluation activities. Key Informant 9 explains the challenges that were experienced in identifying the target population and related issues that arose when evaluation activities commenced.

Existing databases that we have are databases of people in regards to body parts and diagnoses, not of needs. So, there isn’t a real identification of data that can be brought forward in terms of responsive behaviour.
The only thing that we have is in the InterRAI [community health assessment system], and some of the data collection ... of some crude measures, but they’re not universal and they don’t go across sectors. So, if you look at the Hay [interim evaluation], what they were trying to do was to try to define this population in proxy measures. The other part was – and this is what I mean by “sector things”... the interest for evaluations [is] very different depending upon who the recipient of the evaluation is. So, in regards to the province, they were very interested in specific indicators – and cost, of course. So the issues were – do we have some indicators in regards to the number of people going to emergency, effect on ALC, long-term care, decreased long-term care transfers, et cetera. The difficulty with that, if you can imagine, is there’s maybe, in our area alone here, 20 or 30 initiatives that are looking at trying to decrease ALC, or emergency, effective emergency use or diversion. So, how do you pull out the ... cause and effect in regards to that project?

... there was a year and a half of looking after the Hay Group of legacy indicators and I think we’re back at square one, trying to sort out ... if [BSO] is a catalyst for change and it is to support the system and it is for service coordination and increased capacity, what are the appropriate indicators? Having said that, I just [had] a call two evenings ago with British Columbia and Nova Scotia and Alberta, and they’re having the same problem in terms of ... trying to identify ... the evaluation indicators.

The other two parts, though, [are] finding other databases that have to do with emerging activities, and data that have to deal with quality improvement strategies. Looking at clinical outcomes as well as health care satisfaction or experience outcomes, and finding some global instruments that can be picked up by the BSO across the province. So, it’s a long ways to tell you that as far as those three things in the evaluation, as far as (1) health care experience, (2) clinical outcomes, [and] (3) systems indicators, we’re still in a process of trying to find the best way to do that (Key Informant 9).

There was some discrepancy in the key informants’ understanding of the evaluation process. All were aware that some sort of province-wide evaluation was to take place, but the mechanism of the evaluation and the sample of LHINs to be involved was not clear. Key Informant 6 indicated a provincial evaluation, but then noted that it would only include the early-adopter LHINs. By definition, the evaluation cannot be considered “province-wide” if it only includes four LHINs:

We also did, you know, just a small evaluation, called activity measures. So, we do quarterly reporting to BSO ... we have a number of different measures of basic activity. They’re not really [an] evaluation, but they’re evidence that things are starting to change in the system. And those are based on our quality improvement activities. So, that’s the smaller piece of the local evaluation, but BSO will be evaluated provincially. And, you know, I better get my facts straight. I think, just before, early adopters were involved in that evaluation, not all 14 (Key Informant 6).

Key Informant 4 explained how the evaluation focus changed over time. Actors involved in the implementation of BSO were made aware of the various evaluation activities. As implementation
continued, this informant saw a decline in the emphasis on communicating evaluation-related activities. In addition to the Hay Group interim evaluation, some LHINs conducted local evaluations to assist with future LHIN planning.

Key Informant 4: I do find that piece [evaluation] has probably been more on ... initially, it was high up on the radar, and every meeting we went to we heard some things. But it feels like that’s been a little bit quieter, of how that’s all starting to roll out. I know, locally, we are looking at evaluation within each long-term care home, and then trying to look at the community piece and a broader system piece locally, that we will evaluate how it works and pull on some of our agencies that have access to that whole QI evaluation position. But I think provincially ... I would have to be really honest, that’s the piece I feel still has ... it’s a bit fuzzy for me.

Interviewer: Do you know if the local evaluation … is that something that is mandated for all the LHINs or is it something that each LHIN has decided to take up … on their own?

Key Informant 4: I mean, I think the one in Mississauga took it up on their own, is my understanding. Because Waterloo, the Research Institute for Aging, contacted us as well to see if we wanted to be part of it. So I know they’ve taken it up on their own to try and look at it locally. And I don’t know that every single LHIN is doing it. I think people are waiting to hear how that whole provincial evaluation was going to roll out.

I think there’s richness in the larger BSO, how did it all roll out provincially but I do think each community has its uniqueness. So, hopefully, people will see the importance of evaluation.

Related to what was presented above by Key Informants 9 and 4, Informant 7 expands on their particular LHIN’s evaluation activities and connects this to the use of province-wide “legacy indicators.” The Ministry and the LHINs were to use these indicators to understand the impact of the BSO initiative on the target population. A total of eight indicators were reported within the Hay Group interim evaluation (Hay Group, 2012, p. 73).

Currently there’s an evaluation being conducted in our LHIN on our BSO action plan. Other LHINs are conducting similar evaluations based on their models and stuff like that. I actually just got off a phone call this morning about legacy indicators going forward and that the Ministry of Health will have a portal for, you know, LHINs to go in and look at legacy indicators. And we’re looking at probably about five legacy indicators that will talk about things like hospitalizations and ALCs and all that kind of ... you know, ALC days and stuff like that (Key Informant 7).
7.3.3 Perceptions of PSWs

The third emergent theme related to the changed perceptions of PSWs by other health service provider workers and administrators. Two informants noted in their reflections that throughout the implementation of the BSO initiative, there was a change in the perception of PSWs. Key Informant 3 explained a shift in their perception to place a higher value on the knowledge held by PSWs, and that this change showed an increasing respect for the role of the PSW as a care provider.

*I think the other thing that’s potentially a barrier but also a positive with BSO is that it’s really enhancing the perception of personal support workers and really placing value upon the knowledge that they hold, and the solutions and tools that they can utilize to address responsive behaviours. And so that is somewhat of a challenge too, because traditionally they have not been viewed as the go-to person and they are in fact one member of our teams that are going out to the homes. And so they have that peer-to-peer mentorship and so forth. And, you know, for some physicians and so forth, and nurses and such, that interdisciplinary respect, you know, is being worked on* (Key Informant 3).

Similarly, Key Informant 4 spoke to how PSWs have been empowered through BSO, and that this was an unintended outcome of the initiative that could be considered a success.

*I think it’s empowered ... especially the PSWs. It’s been fascinating to watch the PSW be very validated for their roles and their functions. And they’re very knowledgeable. And we’ve had PSWs present to the whole long-term care sector on successes in their long-term care homes. And that has probably been one of the most rewarding things to witness ... seeing people who do the hands-on, practical, day-to-day work really be valued for their role and be able to share with others to teach others. And so that’s been a real success* (Key Informant 4).

One of the goals of the BSO initiative was to increase the skill sets of PSWs and other direct-service provider staff while enhancing system capacity to effectively address responsive behaviours. However, discovering that perceptions of PSWs had changed and resulted in more respect for the PSW role itself among other care providers was a positive unintended outcome of the implementation process itself.
Chapter 8
Discussion

This thesis asked two questions: (1) What factors led to the development of the Behavioural Supports Ontario initiative, and (2) What factors had an impact on how the Behavioural Supports Ontario initiative was implemented? This chapter provides a summary of the research findings, an interpretation of what these findings mean to understanding the development and implementation of the BSO initiative, the contributions and limitations of this thesis, and future research considerations.

8 Discussion

In response to the first research question, this thesis argues that the BSO initiative was developed as a reaction to an increased awareness of the impact of responsive behaviours on patient/staff safety and health system performance. The findings support this hypothesis by identifying several factors that led to the development of the BSO initiative: the inability to provide appropriate care to people with responsive behaviours was catapulted onto the provincial government’s agenda by the event at the Casa Verde long-term care home, and further inquiry identified the ineffective use of emergency departments, high numbers of ALC days, uncoordinated care across care provider organizations, and ongoing staffing issues related to lack of time and training on how to provide appropriate care. Overall, health system performance was being affected by the way the current system was providing care to people with responsive behaviours. In addition, staff and patient safety concerns existed due to the risk associated with poorly managed responsive behaviours.

The incident at Casa Verde was significant enough to result in an inquest, and the subsequent coroner’s report identified 65 ways for the MOHLTC to improve its approach to caring for people in long-term care homes. Most of these recommendations focused on areas that BSO was later developed to improve upon: adding more staff; increasing access to training, tools and resources; inserting specialized skills amongst existing staff; and creating specialized units or care teams. This incident, and the resulting recommendations, provided a base for the development of a causal story in order to explain the problem of violence between residents and toward staff in long-term care homes. As Deborah Stone (1989) describes, causal stories provide
a basis through which problems can be explained; the explanations then have one or more potential solutions that should be acted upon. In this case, that causal story was provided by the coroner’s report after the Casa Verde inquest. It indicated that the events of Casa Verde might have been avoided if the staff had the information they needed about the resident’s behaviours, if they had enough staff to provide the attention required for residents with responsive behaviours, if they had the requisite skill set needed to provide appropriate care to this population, and if there was a framework that would set standards and targets for improvement. Not having enough staff with the right skills and the needed specialized units contributed to decreased safety for residents and staff in long-term care.

The policy cycle framework used as a foundation for this thesis identifies that after an issue becomes part of the government’s agenda, a process of problem identification begins. This process allows for movement toward developing solutions to the identified problems based on a valid causal theory. In the case of the BSO initiative, the identified problems included the use of emergency departments in times of crisis, increased ALC days, issues related to uncoordinated care, and staffing issues due to lack of training and insufficient time to implement best practices in dementia care. Supporting the stages of the policy cycle framework, the Ontario government’s process of problem identification and solution formulation resulted in the development of BSO as a potential solution to the problems related to responsive behaviours. The policy development process for the BSO initiative involved a group of stakeholders from the Ontario Alzheimer Society, the North-Simcoe Muskoka LHIN, and the SHRTN Community of Practice on seniors’ mental illness, addictions, and behavioural issues. These stakeholders had direct experience with providing care for people with responsive behaviours, and worked to engage hundreds of others with similar backgrounds throughout the process of developing BSO.

The thesis findings show that the engagement of people with direct experience of these issues was seen as unique among key informants (compared with the AAH strategy), and was noted as a positive experience. Using the policy cycle framework, these stakeholders would be categorized as members of the policy subsystem because of their involvement in the policy formulation stage and their knowledge of the problem area of responsive behaviours and dementia. This policy subsystem was involved in the development of a valid causal theory upon which the BSO initiative was situated. Specifically, that quality care for people exhibiting responsive behaviours is achievable if services across systems are coordinated, service delivery
is integrated, and care providers are knowledgeable and have the capacity to provide such care (Ontario BSS Project Team, 2010).

Once a policy is developed, decision makers decide which action to take. In the case of BSO, the MOHLTC committed early funds to begin implementing the initiative. When compared to the experience of developing the AAH strategy, key informants stated that the AAH strategy was imposed from the top down, so that those involved in implementing the strategy were not involved in its development. They felt that process was more traditional in its approach, while BSO’s development was viewed as unique for including a broader base of stakeholders.

The AAH strategy and the BSO initiative were both implemented through the current LHIN structure, but there were key differences: the BSO initiative was found to have used online knowledge exchange to facilitate cross-LHIN communication, required a central body to assess each action plan for cross-LHIN continuity, and balanced the need for province-wide continuity with the need for local flexibility. The AAH strategy development was described by key informants as involving a smaller number of experts acting in an advisory capacity to the policy-makers at the MOHLTC, and was imposed on the LHINs as a package of options that could be delivered within their regions. This thesis did not explore the details of the AAH strategy to confirm the perceptions provided by the key informants, but by their accounts the BSO initiative took a different approach in its development and implementation. The approach used during BSO implementation encouraged and facilitated cross-LHIN communication and sharing. This was seen as a positive way to overcome the geographic boundaries that regionalize the province of Ontario. Facilitating this cross-regional communication and sharing aligns with Sabatier and Mazmanian’s (1980) notion that a successful implementation process must be structured to overcome existing barriers; in this case it was necessary to overcome the regional divides that exist in Ontario in order for BSO implementation to be successful.

In response to the second research question posed, this thesis argues that the implementation of the BSO initiative was influenced by the structure of Ontario’s health and social care systems, by the resources available to achieve system redesign to address responsive behaviours, and by the ability of service providers to carry out implementation activities. The findings support this hypothesis in several ways. First, the financial resources to implement the BSO initiative grew tenfold (from $4 million to $44 million); thereby expanding the number of new hires under the
An initiative from 70 to 700 staff members across long-term care and in the home and community care sector. Having funding available to hire more workers is likely something a long-term care or home and community care service provider would welcome. They are operating at a time when the provision of public funds is often constrained, and public need for long-term care and home and community care is growing due to changing demographics. The money that flowed through the initiative was intended to facilitate a change in how responsive behaviours are understood: instead of being a physiological symptom of dementia or another condition, behaviours were to be interpreted as a form of communication from a person no longer able to verbally communicate their needs. Within the findings, key informants argued that in some instances, long-term care homes would view the addition of a BSO personal support worker “as just another worker” and assign them work unrelated to their BSO role. The tight budgets for service provision have created situations where there is a risk of policy conversion, as BSO-funded positions are used to meet other staffing needs within the organization.

Second, the implementation plan for the BSO initiative required LHINs to learn from each other and communicate across boundaries about successes and learning opportunities throughout implementation. As described in the findings, this was achieved by using an online knowledge exchange platform that hosted meetings, webinars, and learning events for providers, LHIN employees and members of the BSO leadership groups. Sharing action plans and participating in monthly meetings was required at the LHIN level and community/provider level to minimize the risk of having the initiative be implemented in a way that wasn’t in line with the BSO framework for care. A structured and defined implementation process that works toward a specific goal, like the above goal of minimizing the effect of regional variation, supports Sabatier and Mazmanian’s (1980) theory that having a favourably structured implementation process increases the likelihood of the policy achieving its stated objectives. The implementation process was structured so that the CRO would review all LHIN action plans, the LHINs would meet and share implementation updates to enhance communication and share problem-solving approaches, and front-line staff would participate in ongoing quality improvement initiatives that allowed tweaks to be made along the way in order to improve the implementation process.

Third, the ability of workers to carry out implementation activities associated with their LHIN’s action plan was influenced by how workers perceived their ability to keep up with the many changes they were experiencing. The findings show that from the perspective of front-line
workers and administrators at service provider organizations, there have been a number of strategies and initiatives implemented over the years and they are feeling a certain level of implementation fatigue. This relates to the other non-statutory factors that can influence implementation, according to Sabatier and Mazmanian (1980). Among the non-statutory variables they identify that can influence the implementation process, one is the attitudes and resources among constituency groups. The workers who deliver direct care are one constituency group that was identified in the data as having the ability to influence whether the BSO initiative achieves its stated objectives of improving care through better coordination, improved skill sets, and additional human resources. This group is feeling overwhelmed by implementation activities related to several overlapping government initiatives. They assert in the findings that even though they support the BSO initiative and what it is trying to do, the workers on the front line may simply be too overwhelmed to provide the type of focused and targeted care required to effectively support people with responsive behaviours. This finding is consistent with the sentiment found in the literature that across publicly funded health systems, there is increased pressure to provide high quality care with constrained financial resources (Ontario Council of Hospital Unions, 2014); likewise, many feel there aren’t enough direct care providers to allow for the longer time required to provide best practices in dementia care (Tierney and Cummings, 2013). Other findings – for example, on the high rate of turnover and the risk of knowledge discontinuity/loss when a trained PSW or other direct care provider leaves their position – would also be considered non-statutory variables as identified by Sabatier and Mazmanian (1980) that affect the ability of a policy to meet its stated objective of increasing the skill sets of the direct-care provider workforce.

The policy cycle framework is useful for understanding how policies are developed and implemented, but as noted in section 3.1, it is rarely a straightforward and linear process. Among the findings, two lessons emerged in the thesis. They assert that (1) there will be planned activities that are unable to be completed and result in unmet policy goals, and (2) there will be unintended outcomes of the policy that were not originally identified as policy goals. The first lesson shows how the policy-making process can fail to meet stated policy goals. In this case, the BSO initiative failed to meet its intended goal of a province-wide full scale evaluation of the effectiveness of the BSO framework in achieving system redesign. Instead, evaluation activities throughout and after implementation allowed for important learning and tweaking of approaches
as implementation progressed. The use of activity measures during implementation and quarterly reporting allowed staff to see the marginal effect of this policy on the target population within their LHIN.

The Hay Group finalized the initial interim evaluation of the four early-adopter LHINs in March 2012; this report also committed to a final, province-wide evaluation (Hay Group, 2012). Though this final evaluation was expected to be available in December 2013, it could not be located by the time of study completion. Instead, the final quarterly report was available as a final implementation report, but the report presented summary information on implementation and sustainability planning; it did not fully evaluate the impacts of the BSO initiative. This may be due to the timeline of implementation moving ahead several months for the remaining ten LHINs, as the MOHLTC committed extra funds to expand BSO in long-term care. The presence of an upcoming election may have had an impact on the timing of province-wide implementation and the resulting loss of a final evaluation. Instead of a province-wide evaluation, each LHIN was able to choose whether to conduct one individually.

The challenge of identifying the BSO target population was discussed at length in the interim evaluation report (Hay Group, 2012). Since the team that developed the BSO initiative did not want to burden front-line staff with additional assessment and record-keeping, the goal was to have the target population for the BSO initiative identified within existing databases and that data was to be analyzed to evaluate the impact of the initiative. The nature of assessing the impact of a policy within the context of multiple and competing priorities meant that the evaluation team had to determine a way to identify the target population within existing databases used throughout the health system; the thesis findings affirmed that this was a major difficulty in the evaluation process. This was because the information collected in existing databases focused on primary diagnosis or the primary reason for seeking services such as the emergency department – rarely were responsive behaviours identified in this way.

The second lesson found in the findings was that there will likely be some outcomes that are not stated policy goals. One of BSO’s stated goals was to develop knowledgeable care teams by providing targeted training to existing direct-care workers and hiring additional workers with specific strengths and skills in the delivery of best practices in dementia care. The focus was on quantifying the number of staff members hired and trained as an implementation activity, and not
on evaluating the perception of these additional skilled workers by other staff members. But the key informant data identified an unintended outcome – the BSO initiative enhanced the perceived value of PSWs to others involved in the provision of dementia care. As discussed in section 4.2, and supported by the findings in section 7.2.3, the turnover rates of PSWs and the relatively short supply of workers in some regions of the province can result in knowledge discontinuity when a person leaves their position after receiving training from their organization through BSO. This thesis did not intend to evaluate the effects of improved perception of the PSW role in dementia care; however, this would be an interesting research topic to explore given the increased need for skilled PSWs as the population ages and personal care is increasingly being provided in the home, community and long-term care sectors.

As presented in section 3.3, Sabatier and Mazmanian (1980) developed their conceptual framework for policy implementation by analyzing the implementation processes of many policy case studies and identifying common variables present among them. The implementation process presented in their framework incorporates several variables that influence implementation, but not all will be present in every case. In the case of the BSO initiative there were variables within Sabatier and Mazmanian's (1980) framework that were present, lending strength to the framework's applicability. Examples of the variables present in the BSO case include, (a) having a clear set of policy goals that are consistently applied across regions within the jurisdiction (in this case the province of Ontario), (b) having a sound theory which identifies the principal factors and causal linkages that could affect achieving policy goals (in this case that improvements in care are possible starting with a change in how responsive behaviours are understood), and (c) having active support from implementing actors (in this case evidenced by how engaged actors were in the online knowledge exchange platform). The framework asserts the presence of these variables bodes well for BSO's successful implementation over time.

The application of Sabatier and Mazmanian's (1980) conceptual framework also highlights a potential risk to the BSO initiative's long-term implementation. They note that successful implementation over time requires ongoing support for addressing the issues identified in the earlier stages of the policy cycle. Specifically, that decision-makers need to remain focused and committed to the policy being implemented. One of the findings of this thesis identified that implementation fatigue was present for some of the actors involved in implementation. The presence of implementation fatigue was identified by informants in section 7.2.2 as being caused
by having to implement several initiatives at the same time. This could be an indication of
decision-makers continuously working to create change during their time in power. If this is the
case, there could be a risk that in an effort to continuously improve the health system, the
attention of decision-makers may shift and long-term support for the BSO initiative could waver.

The alignment of this case with the theories and concepts explained above underscore that the
BSO initiative is a practical example of the policy-making process, and provides insights into the
specific use of causal stories at the agenda-setting stage. In addition, the findings illustrate the
challenges that can arise during implementation of a policy initiative and the changes in
implementation that can happen along the way.

8.1 Study Contributions

The BSO initiative was the first clear effort to improve the system of care for people with
responsive behaviours in Ontario; a subset of the aging population with specialized needs.
Because of this, the findings of the thesis (which identified a causal story that catalyzed action
and the ways the initiative needed flexibility throughout implementation) may influence the
approach taken by stakeholders and decision-makers in relation to other initiatives which have
identified problems that share similarities with BSO; whether that be for issues related to seniors
and aging, or for issues related to behaviours displayed by other sub-populations in other age and
condition groups (e.g. children with behaviours connected to autism or other conditions), or for
issues that bridge the health and social care divide (e.g. mental health services).

This case study is timely as jurisdictions across Canada and around the world develop solutions
to similar issues related to aging, dementia and responsive behaviours. As the presence of
responsive behaviours increases with the growing population of people living with dementia,
policy-makers will likely be looking to learn about the processes involved in developing and
implementing solutions to improve care for this sub-population while also reducing the system-
wide impacts responsive behaviours can have. Documenting and analyzing the experiences
surrounding the BSO initiative is a step toward providing insight into policy initiatives in this
area of care provision. Conceptually, this case asserts that it is possible to implement an initiative
that can coordinate activities across regional authorities (such as the LHINs in Ontario) that also
allows for local flexibility in the types of intervention activities implemented. These findings
may be helpful in a practical way to other jurisdictions who also have complex systems of care,
and who are trying to address problems that bridge the health and social care divide. These findings may also be helpful to policy-makers in Ontario, as they attempt to tackle other issues that straddle the health/social care divide while also balancing the regional variations of the province.

The findings of this thesis also contribute to understanding the BSO initiative as one approach to policy-making that can be modeled by other jurisdictions looking to develop and implement an initiative that aims to change a system-wide response to caring for people with responsive behaviours.

8.2 Study Considerations and Limitations

This thesis used case study methodology to better understand the process of developing and implementing the BSO initiative in Ontario. Case study methodology is a powerful way to focus in on a particular issue in order to understand it in great depth (Neuman, 2006). In order for it to be a successful method of research it is necessary to identify a case that is rich in information to allow for substantial analysis (Noor, 2008). This is because the interest here is not always hypothesis testing, but on insight, discovery and interpretation (Noor, 2008). This methodology was determined to be appropriate because of the relative gap in knowledge about the development and implementation of the BSO initiative specifically, as well as a general knowledge gap regarding the implementation of initiatives within Ontario’s current LHIN structure. It allowed for a deeper understanding of the factors that led to BSO’s development, as well as the potential for certain factors to influence the implementation of this policy at a time when policy solutions to complex problems relating to seniors and dementia are becoming increasingly important worldwide.

Though the findings may not be transferable in a specific sense, they are supported by the conceptual and theoretical perspectives on policy development using the policy cycle framework, on policy implementation, and on the process of agenda setting. The findings of this thesis support the idea that policy-makers can aim for a balance between local context and provincial or jurisdictional oversight when developing and implementing initiatives across diverse regions. Flexibility to local needs and a focus on equity while aiming for complementary levels of service across regions are important considerations that policy-makers in other jurisdictions may need to make as they attempt to respond to similar issues related to best practices in dementia care.
delivery. Regardless of the type of government and structure of the health system in another jurisdiction, the findings support the theoretically-based position that policy-making requires a problem be identified, come to be on the government's agenda, supported by relevant stakeholders, and implemented in a way that has a solid chance of achieving the policy's goals. This shows how the concepts of causal story development in agenda setting, policy development, and the variables that affect implementation can transcend jurisdictional boundaries.

This thesis used a convenience sample of senior-level staff as key informants for this case study. Though this method of sampling limits the transferability of the researcher's findings, this method was used because this study began while the BSO initiative was being implemented. It was a challenge to identify potential key informants, so the researcher concluded that using the professional network of one central stakeholder would allow access to the people involved in the development and implementation processes. Their access to the knowledge needed to respond to the research questions was essential, and snowball sampling allowed for access to these hard-to-find stakeholders. This approach to sampling allows for access to specialized knowledge, but it also limits the perspectives represented by informants to this one group. The perspectives of other stakeholder groups are not reflected in these findings. It would be of interest to conduct a future study that asked questions about the BSO initiative to other stakeholders including caregivers and PSWs. Their direct experience would enhance the findings of this thesis.

8.3 Future Research

In addition to the above mentioned research project, the completion of a full, province-wide evaluation on the effectiveness of the BSO initiative is a logical next step for future research. Due to the challenges experienced by the Hay Group in accurately identifying the target population within existing administrative databases, it will be important to consider how to overcome the reality that existing sources of data collection do not allow for this population to be readily identified. Developing a way for the target BSO population to be identified would enhance any future research that evaluates the impact of the initiative.

Building on the findings regarding the perception of PSWs as part of an effective dementia care team, useful further research could examine turnover rates and whether perceptions of the increasing value of the PSW role may reduce those rates. Growing the supply of skilled PSWs is of interest to health systems that rely on these unregulated workers to provide the majority of
direct personal care. It would be beneficial if research explored ways to increase staff satisfaction and reduce turnover rates.

This thesis identified the increased awareness of responsive behaviours after the Casa Verde case and other issues with health system performance as factors leading to the development of the BSO initiative. Although the findings did provide insight into the process of developing this policy initiative, there is a question that could be explored in a future research project. The literature identified a person-centred approach as important to the effective provision of dementia care, and within the data presented in the findings, person-centred approaches to care were discussed and BSO was identified as a facilitator of person-centred care for people with responsive behaviours. This researcher is curious to know whether the government’s decision to fund the implementation of the BSO initiative was influenced by their own commitments to move toward a more person-centred health care system, and whether the alignment of the Ontario government’s bigger-picture priorities with the stated goals of the BSO initiative that support person-centredness increased the likelihood of it being funded?

8.4 Conclusion

This thesis involved conducting research to identify the factors that led to the development of the BSO initiative, as well as identifying the factors that may have influenced its implementation. The factors that led to the development of BSO were found to be the raised awareness of the negative effects of inappropriate care when the Casa Verde incident triggered a coroner’s inquest, the ineffective use of emergency departments, high numbers of ALC days, uncoordinated care across care provider organizations, and ongoing staffing issues related to lack of time and training on how to provide appropriate care to people with responsive behaviours. The factors that influenced the implementation of the BSO initiative include the targeting of money toward long-term care as the provincial government increased the amount they would fund tenfold, the initiative’s effects on implementation fatigue and loss of knowledge if staff leave their positions after receiving BSO training, and the risk of policy conversion as funds that flow through the BSO initiative are treated as another source of funds and the framework for change that the BSO initiative provides is swallowed by the increased demands on service providers to do more with constrained budgets. These findings lend support to the concept of causal stories in agenda setting, and theories of policy implementation within the policy cycle.
framework that were used to develop the theoretical framework for this thesis. The findings support the original hypotheses that the BSO initiative was developed as a reaction to an increased awareness of the impact of responsive behaviours on patient/staff safety and health system performance, and that the implementation of BSO was influenced by the structure of Ontario’s health and social care systems, by the resources available to achieve system redesign to address responsive behaviours, and by the ability of service providers to carry out implementation activities.


Office of the Chief Coroner. (2005). *Inquest Touching the Death of Ezz-El-Dine El-Roubi and Pedro Lopez: Jury Verdict and Recommendations*. CC0 010 (Rev. 02/04), Chief Coroner,


Appendix A

List of Documents Analysed


Appendix B

Interview Guide

Date:
Name:
Title:

Study background:

This thesis aims to determine whether Behavioural Supports Ontario is an example of a health policy that has transformed the health system response to people with responsive behaviours. The researcher has conducted a review of the literature and it is clear that the system to support people with responsive behaviours is fractured and uncoordinated. Recently, the Ontario Government invested $44 million in a comprehensive system design known as Behavioural Supports Ontario (BSO). The idea is to reinvent the system of care for people across Ontario who have responsive behaviours. The researcher is interested in learning how BSO was developed and implemented and is conducting interviews with key informants to collect information.

Questions:

1. From your perspective, what is the role of Behavioural Supports Ontario?

2. What gaps in service is it intended to remedy? How?

3. From your perspective, how will BSO alter the current health system for people with responsive behaviours who live in the community?

4. How does this compare to other government strategies (e.g., Alzheimer strategy, AAH, wait times/ALC strategy)?

5. What do you see as the potential barriers for BSO to be considered successful?

6. Do you have any knowledge on how BSO will be evaluated?

7. What needs to be seen for BSO to be considered a success?

8. Anything else you would like to comment on or share?
Appendix C

Consent Form

Purpose

This thesis aims to determine whether Behavioural Supports Ontario is an example of a health policy that has transformed the health system response to people with responsive behaviours. The researcher has conducted a review of the literature and it is clear that the system to support people with responsive behaviours is fractured and uncoordinated. Recently the Ontario Government invested $44 million in a comprehensive system design known as Behavioural Supports Ontario (BSO). The idea is to reinvent the system of care for people across Ontario who have responsive behaviours. The researcher is interested in learning how BSO was developed and implemented and is conducting interviews with key informants to collect information.

By signing this form, I indicate that I understand the following:

Conditions for participating

- My participation is completely voluntary; only the research team will know who has (or has not) participated.
- There will be no negative consequences for deciding not to participate.
- I can refuse to answer any question, stop the interview at any time, leave at any time, and ask that the field notes recording my responses be deleted and not used for this research project, without penalty or consequences.
- I have the right to speak off-record at any time.
- I understand that my name will be removed from the field notes of my interview to minimize any risk that my responses can be identified.
- I understand that the anonymized field notes from my interview will be kept in a locked room that only evaluation team members can access, and that they will be used solely for the purposes of this research project.
- I understand that I can ask to have my responses removed from the research data at any time, provided I contact Delia Sinclair (contact information below).

Risks and benefits

- I understand that the results of this evaluation will be communicated through public presentations and published articles as a resource for caregivers, policy-makers, providers, and researchers.
- I understand that my participation will not affect my employment in any way.
- I understand that I will receive no direct benefits for participating (e.g., fees, gifts).
- I understand that while individuals will not be identified in any report or presentation based on the evaluation findings, it may still be possible for colleagues who know me well to guess my identity.

For more information

- Should you have any questions about the research project, please contact:
  - Delia Sinclair 416-858-6487 or delia.sinclair@mail.utoronto.ca
- This thesis has been approved by our Joint Research Ethics Board. If you have any concerns regarding the ethics of the study, please contact Dr. Ron Heslegrave, Joint Research Ethics Board Chair, at West Park Healthcare Centre (82 Buttonwood Avenue, Toronto ON M6M 2J5) or 416-243-3600 x4333.
……continued

**Summary of the evaluation results**

☐ Please send me an electronic copy of the final research report when it is available (check the box to the left) to the following email address: _________________________________________________________________

I hereby certify that I am signing this form of my own free will, with no pressure from others to do so, and that I do so after having been given all the facts I need to make this choice. In witness thereof, I have signed this form on this, the _____ day of _________________, 201__.

______________________________________________________________

Full Name Signature

Please keep a signed copy of this form for your records. A research team member will ask you to mail or email a signed copy of this form prior to your interview.
Appendix D

Dementia Care Services

The tables below provide details on the dementia-specific services that are available in Ontario, either through the publicly financed health care system, the private market, or some combination of the two. Note that although the stage along the dementia continuum is identified in the tables, this is a generalization and is not illustrative of all cases. This information is adapted from Morton, 2010.

Table D-1 defines and describes the services available to people with dementia. These are considered core services that should be available to all people with dementia in Ontario.

Table D-1: Core Dementia Services – Definition and Description

<table>
<thead>
<tr>
<th>Service</th>
<th>Definition</th>
<th>Description</th>
<th>Likelihood of use based on dementia continuum (stage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult day program for people with dementia</td>
<td>Supervised and supported social and recreational activities provided at a location outside the person with dementia’s home.</td>
<td>Programs generally include meals, transportation to the program, and some personal care. May include light physical activity, assistance with activities of daily living, and minor health care assistance.</td>
<td>Early Intermediate Late (less likely)</td>
</tr>
<tr>
<td>Adult day program with overnight stay for people with dementia</td>
<td>Supervised and supported overnight accommodation at a location outside the person with dementia’s home.</td>
<td>Service includes personal care, meals and appropriate social and recreational activities.</td>
<td>Early Intermediate Late</td>
</tr>
<tr>
<td>Assistive living for people with dementia</td>
<td>Designated housing that provides services and support in congregate or individual accommodation, and can meet the wide range of needs of people with dementia. Within a private retirement home residence.</td>
<td>May include individualized assessment, planning, and a choice of service options, homemaking, light housekeeping, shopping, laundry, personal support, medication monitoring, social activities, nutrition programs, security checks, and planning and coordinating other services that enable independent living. Support service may be available on a 24-hour basis.</td>
<td>Intermediate Late</td>
</tr>
<tr>
<td>Service</td>
<td>Definition</td>
<td>Description</td>
<td>Likelihood of use based on dementia continuum (stage)</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
</tbody>
</table>
| Behavioural unit in a LTC home  | Units specifically devoted to the care of individuals with severe behavioural issues as a result of dementia and/or other neurological or mental illnesses. Generally, these units are secure and provide an array of interventions based on need. | May include assessment, ongoing care planning, interventions, medication and behaviour management. | Late
End-of-life (less likely)                          |
| Dementia-specific education     | Education for people with dementia, caregivers, and the broader community.                                                                                                                                 | May include print and online materials, formal instruction, interactive workshops, or forums. | Diagnosis
Early
Intermediate
Late
End-of-life                                            |
| Dementia-specific friendly visiting | Regular home visits from a dementia-trained volunteer to a person with dementia, to provide companionship and social support.                                                                                     | May take a senior out for activities, such as light shopping or social activities.              | Diagnosis
Early
Intermediate                                           |
| Dementia-specific respite       | Support services for persons with dementia, to temporarily relieve their caregivers.                                                                                                                                 | May include adult day programs, personal care, homemaking, safety checks or social interaction. | Early
Intermediate
Late                                                     |
| Dementia unit in a LTC home     | A unit within a long-term care home specifically devoted to the care of persons with dementia. These units are generally secure (locked) and they may be further subdivided based on the level of care needed. | These units are generally secure (locked) and they may be further subdivided based on the level of care needed. | Late
End-of-life                                             |
| Home help or homemaking for people with dementia | Assisting people with dementia at home with routine household activities including light housekeeping, laundry, and light meal preparation.                                                                                      | May include assistance with banking, shopping and errands, or shopping on the person with dementia’s behalf. | Early
Intermediate                                           |
<table>
<thead>
<tr>
<th>Service</th>
<th>Definition</th>
<th>Description</th>
<th>Likelihood of use based on dementia continuum (stage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient behavioural assessment unit</td>
<td>Units that provide an interdisciplinary evaluation of people with dementia who have complex or severe behavioral issues. The comprehensive treatment plans take into consideration the needs of both the client and caregiver, in order to develop a discharge plan that includes education and referral to community resources.</td>
<td>May include a diagnostic work-up, using various behavioural tools to make a diagnosis, develop a care plan/intervention, and provide medication management. May also include education and transitional plans to discharge patient back to the community/home.</td>
<td>Intermediate Late</td>
</tr>
<tr>
<td>Memory clinic</td>
<td>Outpatient clinics that offer diagnosis, care and support to people who are experiencing memory disorders or some type of dementia.</td>
<td>May include a multidisciplinary approach.</td>
<td>Diagnosis Early</td>
</tr>
<tr>
<td>Personal care or personal support for people with dementia</td>
<td>Assisting persons with dementia with personal hygiene and other activities of daily living.</td>
<td>May include bathing, hair, skin and mouth care, help with toileting, getting dressed, feeding, transferring and positioning, medication reminders, light exercising, and escorting to medical appointments.</td>
<td>Intermediate Late End-of-life</td>
</tr>
<tr>
<td>Support groups for individuals or families providing care to a person with dementia</td>
<td>Support groups for individuals and/or family members who are providing care and support for someone with dementia.</td>
<td>May be formal through an organization, or organically developed in the community.</td>
<td>Early Intermediate Late End-of-life</td>
</tr>
<tr>
<td>Support groups for people with dementia</td>
<td>Support groups for persons who have been diagnosed with a form of dementia.</td>
<td>May be formal through an organization, or organically developed in the community.</td>
<td>Diagnosis Early Intermediate</td>
</tr>
</tbody>
</table>
Table D-2 expands on the information provided in Table D-1 by identifying how services are accessed, delivered and funded.

**Table D-2: Core Dementia Services continued – Access, Delivery, Setting, Financing**

<table>
<thead>
<tr>
<th>Service</th>
<th>Access</th>
<th>Delivery</th>
<th>Setting</th>
<th>Financing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult day program for people with dementia</td>
<td>Direct contact; CCAC referral</td>
<td>Private delivery in the community</td>
<td>Community organization</td>
<td>Private funds, usually not-for-profit; subsidies available based on financial need.</td>
</tr>
<tr>
<td>Adult day program with overnight stay for people with dementia</td>
<td>Direct contact; CCAC referral</td>
<td>Private delivery in the community</td>
<td>Community organization</td>
<td>Private funds, usually not-for-profit.</td>
</tr>
<tr>
<td>Assistive living for people with dementia</td>
<td>Direct contact</td>
<td>Private delivery in the community</td>
<td>Residential facility</td>
<td>Private funds, usually for-profit</td>
</tr>
<tr>
<td>Behavioural unit in a LTC home</td>
<td>Referral from LTC home/CCAC</td>
<td>Private delivery in the community</td>
<td>Residential facility</td>
<td>Private funds for residential costs; public funds for medical costs.</td>
</tr>
<tr>
<td>Dementia-specific education</td>
<td>Internet; CCAC referral; direct contact</td>
<td>Through knowledge exchange channels online and in-person; print; web-based; course-based</td>
<td>Online; community organization; educational facility</td>
<td>Private funds; charity</td>
</tr>
<tr>
<td>Dementia-specific friendly visiting</td>
<td>Community organization; direct contact</td>
<td>Private delivery in the community</td>
<td>Person’s home; residential facility</td>
<td>Private funds; charity</td>
</tr>
<tr>
<td>Dementia-specific respite</td>
<td>Through CCAC; direct contact</td>
<td>Private delivery in the community</td>
<td>Community organization; person’s home; residential facility</td>
<td>Public funds; private funds</td>
</tr>
<tr>
<td>Dementia unit in a LTC home</td>
<td>Through CCAC</td>
<td>Private delivery in a LTC home</td>
<td>Residential facility</td>
<td>Public funds</td>
</tr>
<tr>
<td>Home help or homemaking for people with dementia</td>
<td>Direct contact; through CCAC</td>
<td>Private delivery</td>
<td>Person’s home</td>
<td>Private funds; public funds</td>
</tr>
<tr>
<td>Service</td>
<td>Access</td>
<td>Delivery</td>
<td>Setting</td>
<td>Financing</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>------------------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>In-patient behavioural assessment unit</td>
<td>Through LTC or CCAC referral</td>
<td>Private delivery</td>
<td>Residential facility</td>
<td>Public funds</td>
</tr>
<tr>
<td>Memory clinic</td>
<td>Through primary care provider</td>
<td>Private delivery in the community</td>
<td>Physician’s private practice; community health centre; nurse practitioner-led clinic</td>
<td>Public funds</td>
</tr>
<tr>
<td>Personal care or personal support for people with dementia</td>
<td>Direct contact; through CCAC; in LTC home</td>
<td>Private delivery</td>
<td>Person’s home; residential facility</td>
<td>Private funds; public funds</td>
</tr>
<tr>
<td>Support groups for individuals or families providing care to a person with dementia</td>
<td>Direct contact; community organization</td>
<td>Private delivery</td>
<td>Community organization; person’s home</td>
<td>Private funds; charity</td>
</tr>
<tr>
<td>Support groups for people with dementia</td>
<td>Direct contact; community organization</td>
<td>Private delivery</td>
<td>Community organization; person’s home</td>
<td>Private funds; charity</td>
</tr>
</tbody>
</table>
Table D-3 defines and describes the non-dementia specific services available to people with dementia in a complementary manner to the core services identified in Table D-1.

**Table D-3: Non-Dementia Specific/Complementary Services – Definition and Description**

<table>
<thead>
<tr>
<th>Service</th>
<th>Definition</th>
<th>Description/may include</th>
<th>Likelihood of use based on dementia continuum</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nursing</strong></td>
<td>Trained professionals providing assessment, care and treatment of health condition and health promotion, to reach or maintain optimal health.</td>
<td>May include supportive, preventive, therapeutic, palliative and rehabilitative nursing. May include specialty nursing services and wound care.</td>
<td>Diagnosis Early Intermediate Late End-of-life</td>
</tr>
<tr>
<td><strong>Palliative care</strong></td>
<td>A combination of therapies delivered by a multidisciplinary health/social team, intended to comfort and support individuals who are dying from a progressive, life-threatening illness, as well as their families.</td>
<td>Focus is on minimizing pain and maintaining quality of life. May include hospice care, plans for palliative care unit admission, Do Not Resuscitate orders, living wills, and bereavement support for caregivers. Not all palliative care services will serve people with dementia.</td>
<td>End-of-life</td>
</tr>
<tr>
<td><strong>Social work</strong></td>
<td>Trained professionals providing support and counselling to help people develop and maintain the skills and abilities needed to function as independently as possible.</td>
<td>May address a variety of social, economic and personal needs, including adjusting to chronic illness, elder abuse, providing care to a senior, advocacy, service referral, information and education.</td>
<td>Diagnosis Early Intermediate Late</td>
</tr>
<tr>
<td><strong>Specialized geriatric services</strong></td>
<td>A variety of health care services that diagnose, treat and rehabilitate frail seniors with complex medical, functional and psychosocial issues.</td>
<td>Services provided in the senior’s home, in inpatient or clinic/outpatient settings by a multidisciplinary health/social team.</td>
<td>Diagnosis Early Intermediate Late</td>
</tr>
<tr>
<td><strong>Transportation</strong></td>
<td>Rides for seniors who do not have their own method of transportation. Transportation is provided by staff or volunteers.</td>
<td>Rides are provided to medical or therapy appointments, shopping and various social activities and programs. May include escort assistance for frail seniors who need more “hands-on” help and transfer support.</td>
<td>Early Intermediate Late</td>
</tr>
</tbody>
</table>
Table D-4 expands on the information provided in Table D-3 by identifying how services are accessed, delivered and funded.

<table>
<thead>
<tr>
<th>Service</th>
<th>Access</th>
<th>Delivery</th>
<th>Setting</th>
<th>Financing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing</td>
<td>Hospital; in LTC; CCAC referral for home care; other clinic or community organization</td>
<td>Private delivery</td>
<td>Residential facility; hospital; person’s home; clinic or other community organization</td>
<td>Public funds</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Referral from physician or CCAC; based on prognosis</td>
<td>Private delivery</td>
<td>Residential facility (hospice, LTC home); hospital; person’s home</td>
<td>Public funds for medical costs, some home care services, some medications; private funds for services, medications, related supplies not covered by public funds</td>
</tr>
<tr>
<td>Social work</td>
<td>Direct contact; through CCAC, hospital, clinic or other community organization</td>
<td>Private delivery</td>
<td>Residential facility; hospital; person’s home; community organization</td>
<td>Private funds; Public funds</td>
</tr>
<tr>
<td>Specialized geriatric services</td>
<td>Referral through physician, CCAC, hospital, outpatient clinic. Self-referral possible sometimes</td>
<td>Private delivery</td>
<td>Residential facility; hospital; person’s home; community organization</td>
<td>Public funds</td>
</tr>
<tr>
<td>Transportation</td>
<td>Direct contact; through CCAC, municipality or community organizations</td>
<td>Private delivery</td>
<td>Community or personal vehicle</td>
<td>Private funds; subsidies available based on need</td>
</tr>
</tbody>
</table>
Appendix E

Project Reporting and Accountability

BSO Reporting and Accountability Schematic

Appendix F
Coding Framework

Table F-1: Initial coding framework with codes based in concepts from Stone's (1989) *Causal Stories* in the context of the policy cycle framework.

<table>
<thead>
<tr>
<th>Parent Code</th>
<th>Child Code</th>
<th>Description</th>
<th>Example Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>History</td>
<td>Chronology of events</td>
<td>Chronology of events that relate to BSO development</td>
<td><em>They had the early adopters, and then they brought us in. And then they just accepted that everybody was starting to join that really, over time, I think the early adopters and the ones that came on next all blended together.</em></td>
</tr>
<tr>
<td></td>
<td>Policy then and now</td>
<td>Policy decisions that relate to BSO development</td>
<td><em>I think, in our area because we had been involved with Aging at Home ... it was trying to really pull people together and look at what was the needs. And I’m not sure we were ready. Like, we weren’t lined up and ready for that. I think we were lined up and ready for behavioural supports.</em></td>
</tr>
<tr>
<td>Realities of service provision/gaps</td>
<td>Problem identification</td>
<td>The identification of a problem in service delivery and system performance</td>
<td><em>You know if you train people in isolation of one another then they can’t, it’s very difficult for them to implement new learning.</em></td>
</tr>
<tr>
<td>Identified solutions</td>
<td>The identification of solutions to an identified problem</td>
<td><em>So those were the three priorities for the BSO. So integrated service, building the capacity of workers and coordinating the system.</em></td>
<td></td>
</tr>
<tr>
<td>Parent Code</td>
<td>Child Code</td>
<td>Description</td>
<td>Example Quote</td>
</tr>
<tr>
<td>------------------</td>
<td>------------</td>
<td>------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Agenda-setting</td>
<td>Agenda</td>
<td>A list of government priorities</td>
<td><em>There was first a community provincial forum to begin to look at this particular issue and out of that forum Assistant Deputy Minister became the change champion within the Ministry.</em></td>
</tr>
<tr>
<td>Opportunity</td>
<td>Opportunity</td>
<td>A set of circumstances that make influencing the agenda possible</td>
<td><em>Within the Ministry there was somebody who pulled the gaps together and identified – Minister, you can accomplish all of these things if you roll out the BSO project.</em></td>
</tr>
</tbody>
</table>
Table F-2: Initial coding framework with codes based in concepts from Sabatier and Mazmanian's (1980) policy implementation conceptual framework in the context of the policy cycle framework.

<table>
<thead>
<tr>
<th>Parent Code</th>
<th>Child Code</th>
<th>Description</th>
<th>Example Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation</td>
<td>Breaking down silos</td>
<td>Breaking down silos in order to improve the system/Breaking down silos as a way to solve the problems through service planning</td>
<td><em>What I see already and parts of this role in BSO is that it’s breaking down the barriers associated with organizations operating as silos</em></td>
</tr>
<tr>
<td></td>
<td>Funding</td>
<td>Funding provided for BSO implementation</td>
<td><em>And yes, there’s rumblings back and forth all the time depending upon who’s lobbying and what the process is. It’s just this 43 million, actually, it sounds like a lot, but it’s not in comparison to the budget of the Health System.</em></td>
</tr>
<tr>
<td>Government Direction</td>
<td>Whether government provided direction to the BSO implementation process</td>
<td></td>
<td><em>The government had given us three sort of big ticket indicators, you know, reducing hospitalization and all that kind of stuff.</em></td>
</tr>
<tr>
<td>Initial Plan</td>
<td>The initial plan for implementing BSO framework</td>
<td></td>
<td><em>And initially the proposal was that that might occur for approximately a year and then it will spread throughout the province.</em></td>
</tr>
<tr>
<td>Lived Experience</td>
<td>The lived experience of implementing the BSO framework</td>
<td></td>
<td><em>Well, I think it confirmed for me the willingness of workers to change if they’re a part of the solution.</em></td>
</tr>
<tr>
<td>Parent Code</td>
<td>Child Code</td>
<td>Description</td>
<td>Example Quote</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Perceptions of BSO</td>
<td>Ability to affect change - general</td>
<td>Whether BSO is perceived to have the ability to affect change in general</td>
<td>From what I understand I think people are seeing the value in BSO.</td>
</tr>
<tr>
<td></td>
<td>Ability to improve care</td>
<td>Whether BSO is perceived to have the ability to improve care</td>
<td>I think BSO has definitely helped out the day program and we could continue to use that skill and knowledge as a resource.</td>
</tr>
<tr>
<td></td>
<td>Additional Service</td>
<td>Whether BSO is perceived to be an additional service on top of what is currently available</td>
<td>And right away people said - oh here's another project. We're going to do all of this work and then it's going to die basically.</td>
</tr>
<tr>
<td></td>
<td>Awareness</td>
<td>Awareness of providing care to people with responsive behaviours</td>
<td>I think it made everybody more aware of the importance of serving people with responsive behaviours. I think it made people aware of the availability of tools and methods.</td>
</tr>
<tr>
<td></td>
<td>Duplication</td>
<td>Whether BSO is perceived to be a duplication of existing services</td>
<td>Those are all the initiatives that we’ve been managing, for lack of a better word, all at the same time and trying to have … and, you know, they do overlap. There’s lots of areas where they do overlap.</td>
</tr>
<tr>
<td></td>
<td>Funding stream</td>
<td>Whether BSO is perceived to be a source of additional money to close existing funding gaps</td>
<td>So that whole piece of not being pulled off the floor to replace someone because they could be short staffed and sustaining that role of BSO.</td>
</tr>
</tbody>
</table>
Table F-3: Open codes which emerged from the data

<table>
<thead>
<tr>
<th>Parent Code</th>
<th>Child Code</th>
<th>Description</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluation</td>
<td>Evaluation</td>
<td>Any challenges associated with completing evaluation activities</td>
<td><em>The second thing is we had hoped to do a better job of evaluating the impact of BSO.</em></td>
</tr>
<tr>
<td></td>
<td>challenges</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Front-line workers</td>
<td>Perception of</td>
<td>How PSWs are perceived by other members of the care team</td>
<td><em>BSO has really enhanced the perception of personal support workers...</em></td>
</tr>
<tr>
<td></td>
<td>PSWs</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G
Casa Verde Inquest Recommendations

Below are the recommendations from the Casa Verde Inquest report that have been identified as being potential precursors to the BSO initiative. A full list of the 85 recommendations can be found in the report (Office of the Chief Coroner, 2005).

Recommendation 1:

That the Ministry of Health and Long-Term Care (MOHLTC) should give increased priority to the health needs of the elderly and, in particular, the serious challenges faced in treating elderly cognitively impaired residents, by immediately developing and implementing a plan (or "Framework") to ensure appropriate standards, funding, tracking and accountability in Long Term Care (LTC) and other facilities treating such individuals.

Recommendation 18:

It is recommended that the MOHLTC, after appropriate consultation, review eligibility and admissions regulations and policies to ensure that individuals exhibiting or prone to aggression be assessed prior to the eligibility decision and only be placed in specialized facilities or LTC facilities with appropriate specialty units.

It is further recommended that if the decision in made to continue to place individuals in LTC facilities, that the MOHLTC must set standards for these facilities and units to ensure that they are sufficiently staffed with appropriate skilled regulated health care professionals who have expertise in managing these behaviours and at a staffing level that these behaviours can be managed without risk of harm to self and others. If unregulated staff are assisting the regulated health care professional on these specialty units/facilities they must be U-FIRST trained.

Recommendation 22:

The MOHLTC should fund specialized facilities to care for demented or cognitively impaired residents exhibiting aggressive behaviour as an alternate to LTC facilities. Funding for these facilities should be based on a formula that accounts for the complex high-care needs of these
residents in order that the facility be staffed by regulated health care professionals (RN's and RPN's) who are trained in PIECES and in sufficient numbers to care for these complex and behaviourally difficult residents.

Recommendation 33:

Pending the remodeling of the future system and implementation of training for all staff, additional funding must be provided and tracked to ensure that a PIECES trained Registered Nurse at each facility is designated for those residents on each shift, due to the unpredictability of behaviours and level of risk associated with these residents.

Recommendation 40:

The MOHLTC should set mandatory standards and provide designated funding to ensure that all staff interacting with cognitively impaired residents in LTC are PIECES/U-FIRST trained. This includes those individuals who make decisions regarding admission and placement, as well as those managing the individual's care.

Recommendation 47:

That the MOHLTC reinstate funding for all expenses associated with PIECES/U-FIRST training, including travel expenses and wages to backfill for equivalent staff to ensure that all LTC facilities have their staff appropriately trained and continue to have new staff trained.
Appendix H
Glossary of Acronyms

AAH - Aging at Home Strategy
AD - Alzheimer's Disease
ADL - Activities of Daily Living
ALC - Alternate Level of Care
BSO - Behavioural Supports Ontario
CCAC - Community Care Access Centre
CRO - Coordinating and Reporting Office
ER - Emergency Room
FTD - Fronto-Temporal Dementia
HCC - Home and Community Care
HQO - Health Quality Ontario
HSP - Health Service Provider
iADL - instrumental Activities of Daily Living
LHIN - Local Health Integration Network
LTC - Long Term Care
MCSS - Ministry of Community and Social Services
MOHLTC - Ministry of Health Long-Term Care
PSW - Personal Support Worker