Behaviours Have Meaning

The Ontario Behavioural Support System Project

October 2010

Submitted by the Ontario Behavioural Support System Project Team
October 2010

This document contains an overview of the results of the first phase of the project including identified next steps. A companion Appendices document containing further details is also available at www.bssproject.ca .

Table of Contents

Introduction

Ontario's healthcare system does not adequately address the needs of older adults with behaviours associated with complex and challenging mental health, dementia or other neurological conditions. These behaviours include aggression, wandering, agitation as well as others and are a major source of distress both to the person who is presenting the behaviours and to those who experience them – the caregiver, the family members, and the service providers in all sectors of the health care system.

In January 2010, the Ontario Ministry of Health and Long-Term Care provided funding for the first phase of an Ontario Behavioural Support System Project (BSS). The objectives of this phase were to create a foundation for subsequent phases by defining the target population, describing the case for action, proposing a system model and starting to establish an appropriate evaluation and measurement framework. The following report summarizes the work of the first phase. It includes a description of a model designed to create an integrated cross-sectoral system of supports and treatments organized around patients as well as caregivers. It also identifies where we have gaps both in our understanding of the full extent of the problems and the potential impact of change and how we can address these in the next phases of work.

Three different kinds of evidence inform this key work: lived experience, practice based information and research. Throughout this first phase, the Ontario BSS Project has 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 (SHRTN) Mental Health Community of Practice,
- Comments and suggested revisions gained from the volunteer members of the Virtual Advisory Panel
- Feedback from key informant interviews and opinion leaders from targeted sectors
- A literature review of relevant research-based literature and resources

The case for change is self-evident: we need to transform the way we currently provide care and services for this important population. The key stakeholders in Ontario are telling us that they are ready to move forward to create better health, better care and better value for the older adults with behavioural challenges and their caregivers. They are ready to build on the current investments in programs aimed at supporting seniors, to continue to develop and apply their quality improvement skills to identify where the problems are and to work together across sectors to find innovative and lasting solutions.

The approach provided in this report is designed to capitalize on this readiness, address the gaps in knowledge and capacity and provide the leadership both in Ontario and for the nation to move forward together to improve both the patient experience and the

performance of our healthcare system. The readers of this report will not see a list of recommendations for consideration, but rather a series of actions aimed at supporting the Local Health Integration Networks to begin to apply the best practice model in their local environments. As they begin to implement, they will learn more about their gaps and barriers and find ways to integrate and build on their current investments and innovations. Ultimately, we will achieve the vision of a comprehensive behavioural support system in Ontario and better health, better care and better value for all.

The current state in Ontario

The Target Population

The target population for this initiative represents an important high needs/ high cost group of people who require a change in how we provide services and care. As a result, there is a potential for a high impact, if we are able to make the necessary system changes.

Older adults with complex and responsive behaviours associated with cognitive impairments due to complex mental health, addictions, dementia, or other neurological conditions and their caregivers. These adults may be living in long-term care homes or in independent living settings or receiving care in acute care environments.

Older

The target population specifically states "older adults" due to the significant and rapidly growing unresolved demand for care and the major impact this is having on the provincial health care system. We have not defined a specific age range since in some situations an "older" person could include adults with complex and debilitating disorders who may not be over 65years.

Complex and responsive behaviours

The definition includes behaviours that could be dangerous to the person or others and as well could be considered antisocial within environments where people must coexist with others. These types of behaviours include aggressive behaviour (e.g. resisting help with personal care or medications, hitting, scratching, biting, shouting, wandering, and throwing objects) agitation, wandering and others.

Responsive refers to the fact that many of these behaviours could respond to appropriate and timely interventions and may be occurring as a result of an unmet need or desire that can no longer be communicated. To make things more difficult, individuals could also be responding to environmental barriers or approaches from caregivers as they try to communicate their needs. The term challenging behaviour or 'behaviour that challenges' is a term that is often also used, although the term responsive helps us to focus more on what can be done to make change rather than its impact.

Associated with cognitive impairment due to complex mental health, addictions, dementia, or other neurological conditions

Cognitive impairment is the centralizing focus of this target population, but a number of conditions could cause the cognitive impairment. For example, this could include individuals with complex mental health issues where more than one chronic challenge exists; or older adults with cognitive impairment resulting from addictions; or perhaps individuals with Parkinson's disease.

Although other populations are not specifically included, the vision, guiding principles and overall BSS model proposed in this report are likely applicable to other populations with similar challenges such as people with an acquired brain injury, and younger adults with age-related and neurological illnesses. Further discussions and analysis in phase 2 and 3 of the project will identify how the proposed model integrates with these populations.

And their caregivers

The focus on individuals with cognitive impairment and responsive behaviours means as well a necessary focus on their caregivers. The caregivers are often the primary care providers, the care experts and the spokespersons for individuals who cannot speak for themselves and are an integral part of an excellent system of care.

Living in long-term care, acute care or in independent living settings

A focus on just one sector or environment will not solve the problems of this client population. In fact, the transitions and hand offs between organizations and sectors may be the location of most of the problems.

As part of the stakeholder engagement process, the project team shared drafts of the target population definition with groups and individuals representing various related populations. This included for example groups associated with: developmentally delayed seniors, neurological conditions, mental health and addictions and acquired brain injuries. The input and advice of these stakeholders will continue to be needed throughout the implementation of phase 2.

Grounded in a lived experience

The foundation of the outcomes of the first phase of the Ontario BSS project is to provide quality, person-centred care. As such, this report begins with and incorporates throughout, a lived experience to keep grounded in the perspective of the person and his or her care providers including family. Throughout this section, we will learn from the experience of Mr. Walters who represents a common story in the current system in Ontario.

To illustrate further the current state in Ontario, we will focus first on the target population, and a case for action.

The Case for Action

Several key considerations build a case for action in Ontario:

1. The numbers of people at risk for responsive behaviours is increasing
2. Challenges are experienced across all health sectors and services
3. The person and family require better quality experiences
4. There are significant costs associated with managing behaviours
5. There are recognized best practices that could be more systematically adopted
6. There is an opportunity to leverage existing initiatives in Ontario
7. There is a stakeholder readiness for change.

1.0 The numbers of people at risk for responsive behaviours is increasing

The BSS project used currently existing data in order to develop a better understanding of this target population. Although helpful, existing data is not specific and focused for this important population. What we are able to understand is compelling, although what is not known might be of even greater concern.

Mr. Walters is 81 years old and has Alzheimer's disease. He has had a busy and rewarding life. He worked as an Industrial Engineer, raised, and supported his family of seven until he retired. He loved being active and engaged outdoors. His symptoms became noticeable to his family about 7 years earlier when he started to become easily disoriented, couldn't find his way home and frequently lost his belongings. The diagnosis was a shock but the family tried to cope and managed relatively well for the first few years. His wife provided round the clock supervision but was finding it harder and harder to cope with his changing mood and unpredictable behaviours. Mrs. Walters kept wondering how much longer she could cope.

We are just beginning to understand the full impact of the increasing numbers of older persons with dementia on the healthcare system in Canada. Analysts are predicting that in 2038, clinicians will diagnose a new case of dementia every 2 minutes and 1,125,200 Canadians will suffer with dementia[1]. In Ontario, today dementia is the leading cause of admission to long-term care[2] and more than 65% of the population in long-term care (LTC) homes has Alzheimer disease, dementia or other mental health issues[3]. In the community, one in five seniors (20%) receiving publicly funded home care had a diagnosis of Alzheimer's disease and/or other dementia.[4]

Individuals with certain neurological and vascular conditions also can experience cognitive impairments and exhibit responsive behaviours. For example, in one review of Parkinson's disease (PD) it was found that 24 to 31% of PD patients have dementia, and that 3 to 4% of the dementia in the population would be due to PD.[5] Vascular diseases such as stroke or cardiovascular disease are also associated with an increased risk of cognitive impairment in older individuals. [6]

Among the general population of older adults, it is estimated that 15-40% of Canadian seniors require mental health services and that 5-10% have severe psychiatric impairment that may require specialized services.[7] "Mental health problems in late life usually occur in the context of medical illness, disability and psychosocial issues related to social or emotional isolation. Seniors are particularly at risk during critical transitions, including disablement, widow-hood, caring for a spouse with dementia or institutionalization."[8]

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

2.0 Challenges across sectors and services

In April 2007, the report entitled *Building a Better System: Caring for Older Individuals with Aggressive Behaviours in Long-Term Care Homes* was released in response to the results of a

[1] Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer Society of Canada, 2010
[2] Medical Advisory Secretariat MOHLTC, 2009
[3] Ministry of Health and Long-Term Care, Long-Term Care Resident Profile – 1992 to 2006, January, 2007
[4] CIHI Report: Caring for Seniors with Alzheimer's disease and other forms of Dementia, August 2010
[5] Aarsland D, Zaccai J, Brayne C.; *A systematic review of prevalence studies of dementia in Parkinson's disease*. Movement Disorders 2005 Oct;20(10):1255-63
[6] Stewart, R., *Vascular Dementia A disease running out of time*, British Journal of Psychiatry, 2002, 152-156
[7] Cited in: Ontario Behavioural Support System Project: *Proposed Older Adults Behavioural Support System Model: Detailed Working Document* Dudgeon and Reed, Distance Learning Group, July 2010. BSS project Appendices www.bssproject.ca
[8] IBID

Coroner's Inquest regarding the tragic death of two residents killed by a newly admitted resident in a long-term care home in Toronto. Highlighted through this event was the lack of prevention, knowledge, coordination, integration, early identification or adequate supports to safely manage residents with aggressive behaviours or the safety of others in a fragmented, silo-driven service structure. Generic services provided to the elderly do not meet the needs of older adults with responsive behaviours.

About a year ago, the family realized that Mr. Walters only recognized his wife and no longer any other family members. One day his son came for a visit and approached Mr. Walters to speak with him when all of a sudden, Mr. Walters began to punch, scream and kick. Soon the family began to believe that only Mrs. Walters was able to approach her husband to provide care. She became depressed, frightened and exhausted- and could not even take advantage of respite care since her husband sent the caregivers away.

Long-term care homes currently provide care to the largest number of seniors with responsive behaviours. In Canada, the proportion of seniors in residential care exhibiting challenging behaviours is approximately 58%.[9] In a 2010 report from the Ontario Health Quality Council[10] (OHQC) it is noted that behaviours such as aggression, agitation or wandering are common among residents of long term care homes and that about one in nine residents exhibited worsening behaviour over the past three months. One characteristic of behavioural and psychological symptoms of dementia is the intermittent occurrence of severe aggression, which is especially difficult to manage in long-term care homes. The OHQC report also states that 17% of residents are physically restrained which is a much higher rate than in other countries and identifies this as an area where improvement is needed. Staff members who provide care for dementia patients also feel the impact of the behaviours. Among nurses working in hospitals or long-term care facilities in Canada, 34% reported physical assault from a patient over the past year and 47% reported emotional abuse. Registered Practical Nurses were particularly at risk, with 47% reporting physical assault and 72% reporting emotional abuse. [11]

In one analysis of data on the Ontario home care sector, approximately 30% of home care clients with a diagnosis of dementia exhibited some behavioural symptoms.[12]

[9] CIHI Report: Caring for Seniors with Alzheimer's disease and other forms of Dementia, August 2010
[10] Ontario Health Quality Council, "2010 Report on Ontario's Health System", Quality Monitor, 2010.
[11] Margo Shields and Kathryn Wilkins, Health Reports; Statistics Canada: "Factors related to on-the-job abuse of nurses by patients", April 2009
[12] Sinclair, Costa, Harvey, Caffery; "Analysis of Persons with a Diagnosis of Alzheimer's disease or Dementia in Home Care", ASO, September 2010

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.

3.0 Need for better quality care for the person and support for caregivers

Caregivers with lived experience are telling us that we need to make some important changes to address their needs[13]. 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. They would like to see that the design of respite services support their needs and allow them to do important things such as "attend church". They question why they are not receiving timely referrals to groups that exist and can help them. As one frustrated caregiver noted, "No one tells you what services are available until you are so tired and frustrated that you cannot cope yourself ". They are telling us that they do not receive the information and support that they require.

Informal caregivers are critical to helping older adults with behavioural challenges to remain at home. Currently very few seniors who are receiving publicly funded home care are able to manage alone. In a sample across Canada of 131,000 home care clients age 65 and older, only 2% were coping without an informal caregiver[14]. Although almost 20% of the informal caregivers in this sample reported distress in their roles this number rose significantly when caring for seniors with moderate to severe cognition problems (37%). Of great significance is that the highest rates of caregiver distress, at more than 50%, were found among caregivers of home care clients who exhibited verbally and/or physically abusive behaviours—four times the rate for caregivers of clients who did not exhibit these behaviours. It is also interesting to note that persons with moderate to severe behaviours receive no greater level of service than those where behaviours are not present.

In one analysis of home care clients in Ontario, people with serious behaviours received the greatest amount of informal care time at 36.7 hours per week. Based on this information, the amount of hours provided to care for a loved one with serious behaviour symptoms is equivalent to a full-time job[15]. Frustration and fatigue are evident and even if willing to continue, caregivers in the community begin to question their ability to provide the best care. In this analysis, 70% of informal caregivers caring for persons with serious behavioural challenges and 67% caring for those with moderate behavioural challenges indicated that they felt the patient would be better off elsewhere[16]. This kind of fatigue has profound implications for a healthcare system struggling to keep people in the community rather than in institutions.

[13] Conversations about Care: The Lived Experience, the Ontario Behavioural Support System Project, Aug 2010 BSS project Appendices www.bssproject.ca
[14] CIHI Report: Caring for Seniors with Alzheimer's disease and other forms of Dementia, August 2010
[15] Sinclair, Costa, Harvey, Caffery; "Analysis of Persons with a Diagnosis of Alzheimer's disease or Dementia in Home Care", ASO, September 2010
[16] IBID

Long-term care homes in Ontario use restraints more often than they do in most other countries. As well, there is evidence that medications such as antipsychotics and benzodiazepines are used when there was no clear indication for their use. There is room for improvement.[17]

[17] Ontario Health Quality Council, "2010 Report on Ontario's Health System", Quality Monitor, 2010.

4.0 The cost to the system

The annual total economic burden of dementia in Canada is expected to increase substantially from the approximately $15 billion spent in 2008.[18]. The health care system is already feeling the impact of dementia on cost and service utilization. Although likely underestimated due to challenges with collecting full data, the direct cost of delivering health care services and supports to seniors with Alzheimer's and/or Dementia in Ontario in 2009-10 is at a minimum $1.8B.[19]

In acute care, when individuals no longer require acute care hospitalization they are designated alternative level of care (ALC). 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. [20]

When individuals also suffer from responsive behaviours, this may affect the ability of the system to find appropriate and safe long-term care in a timely fashion. 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. [21] 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.[22] Although we do not have the data to demonstrate the full impact of responsive behaviours on the wait time for a long-term care bed in Ontario, estimates are that it may double the average wait of 109 days.

The last few weeks, at home Mr. Walters's behavioural problems continued to get worse including episodes of crying, throwing things all of a sudden and screaming at his wife with his fist raised. One day, he hit his wife and she called their son for help. The son arrived, but his appearance made Mr. Walters even more agitated and they called the police to help them get Mr. Walters to the nearest emergency room. Mr. Walters received medication at the hospital and appeared to be calmer, but the health care team suggested that he needed crisis long-term care home placement.

[18] Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer Society of Canada, 2010
[19] Behavioural Support System Project- Business Case Executive Summary, RWS Advisory, September 2010 BSS project Appendices www.bssproject.ca
[20] Walker, Morris and Frood, "Alternate level of care survey in Canada: A summary". Healthcare Quarterly, 12(2), 21-23, 2009
[21] Ontario Hospital Association ALC Survey Results: July 2010
[22] Costa and Hirdes: *Clinical Characteristics and Service Needs of Alternate-Level-of-Care Patients Waiting for Long-Term Care in Ontario Hospitals*, Healthcare Policy Vol 6, number 1, 2010

With early recognition and specialized geriatric community supports in place, it is believed that the majority of older persons with responsive behaviours can be managed at home. However, today 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.[23]

5.0 Best Practices are available but may not be widely adopted

A rapid literature review commissioned by the BSS project identified a number of best practices in behavioural support services for individuals with dementia.[24] For example, in relation to collaborative care, key elements of interventions were consistent in numerous models and included 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. The literature supported some targeted interventions, although, it did highlight that there are still many opportunities to improve the available empirical evidence. It is essential to know how more about how well the system has implemented these best practices, and to ensure there is a comprehensive system designed to ensure innovations are shared and built on.

6.0 Leveraging existing initiatives

Ontario has made a number of investments over the last several years to address the needs of seniors with dementia- although not specifically focused on the issue of responsive behaviours.

These include:

Ontario Strategy for Alzheimer's disease and Related Dementias: This strategy has added Psychogeriatric Consulting Resources, Staff Education and Training curriculum (PIECES and U-First), the Alzheimer Knowledge Exchange and funding for increased Respite Services for Caregivers.

Aging at Home: Launched in 2007, it is a $1.1 billion (over four years) initiative aimed at supporting seniors to live independent lives in their own homes, avoid unnecessary hospitalizations and help those who are admitted to return home faster. Some of the programs funded serve this population.

Quality Improvement – Investments designed to increase the capacity of the system to identify process challenges to act on changing them. Some examples include: *Flo Collaborative*: a collaborative supported by the Centre for Healthcare Quality Improvement focused on improving flow of medical patients from acute care to the

[23] Dawson, Weerasooriya and Webster. "Hospital Admissions via the Emergency Department: Implications for Planning and Patient Flow." Healthcare Quarterly 11(1): 20–22, 2008.
[24] Behavioural Support System Project: *A Rapid Literature Review on Behavioural Support Services,* May 2010, Dr. Moriah Ellen, Distance Learning Group- BSS project Appendices www.bssproject.ca

Mr. Walter's stay in the long-term care home was extremely difficult. He kicked doors and was unable to be calmed. He kicked a female resident out of her bed so that he could sleep on it himself. The staff attempted to re-direct him, but he became more agitated and aggressive. He tried to leave the nursing home and kicked every door. Reluctantly, the home called the police and again he left for the nearest emergency room.

community; *Residents First*: a collaborative supported by the Ontario Health Quality Council and aimed at long-term care homes; the *Emergency Department Improvement Project;* and the *Quality Improvement and Process Innovation Partnership,* focusing on Primary Care.

Ontario's Emergency Room Wait Time Strategy- which supports both performance of emergency rooms as well as looking at alternatives to ER use and as well improved hospital bed utilization

The investments have led to a relatively strong mix of resources available to assist individuals with behavioural challenges; however, together they do not address the needs of a functioning, integrated system. For example, outreach teams are not currently tied to behavioural units; nor are specialized behavioural resources normally coordinated with either geriatric resources or broader mental health resources. As a result, there is repetition of assessments, lack of coordination of referrals and gaps in service provision. As well, the Aging at Home projects do not have a coordinated evaluation or even a method of sharing results and learnings with other groups with similar challenges. Similarly, there is no consistent uptake among organizations of training opportunities for staff.

Some important recent strategic directions are also creating an environment supportive of change:

Every Door is the Right Door: 10 Year Mental Health and Addictions strategy. It aims to identify mental illnesses and addictions early and to provide high quality, effective, integrated, culturally competent, person-directed services and supports for Ontarians with mild to complex mental illnesses and/or addictions.

Excellent Care for All: The focus on patient centred care and the use of Quality Improvement to support strategic system changes are central to the proposed BSS model.

6.0 Stakeholder readiness for change

Key system stakeholders have been eager to add their projects to the BSS innovation inventory (www.bssproject.ca). The inventory and the Alzheimer

Knowledge Exchange website are essential first steps to support a dynamic exchange of ideas and outcomes. The 21 projects in the initial inventory represent innovative ideas in Ontario aimed at improving the situation for the target population including funded and proposed projects.

A new grassroots effort has been taking hold over the last year. The Seniors Health Research Transfer Network Community of Practice (SHRTN CoP) associated with the Alzheimer Knowledge Exchange is focused on seniors with mental illness, addictions and behavioural issues. With the support of the Ontario Health Quality Council (OHQC), approximately 11 cross-sectoral meetings with about 200 clinicians, administrators and care providers have occurred across the province. These forums had several purposes: develop local partnerships and collaboratives; use a quality improvement approach to address specific improvement challenges; test out a strategy to link policy and practice in target LHINs; and support knowledge exchange.

Nationally the issue has also galvanized stakeholders to action. In the summer of 2010 approximately 40 early leaders from each Canadian province and territory met twice to discuss the current state of behavioural support services across the country. This initiative, co-hosted by Alzheimer Knowledge Exchange and the Canadian Dementia Resource and Knowledge Exchange, demonstrates the stakeholder's eagerness and work together to share concerns and ideas on a national platform.

Summary

Ontario's healthcare system does not adequately address the needs of older adults with behaviours associated with complex and challenging mental health, dementia or other neurological conditions.

The system is fragmented and there are no consistent guidelines or care standards in use.
The experience of patients and caregivers needs to improve.
The system is just beginning to address how to the gather specific information on demographics, utilization, outcomes and cost for this client population and there is a long way to go.
We do not know if the current investments, innovations and projects are making a difference

The story of Mr. and Mrs. Walters is a blend of more than one actual patient experience designed to illustrate what is happening now. If we imagine a different future, Mr. and Mrs. Walters would have the support of an interdisciplinary response team connected to the local behavioural support unit with the knowledge and expertise to deal with their escalating needs. Their Care Coordinator would provide continuity and support both in their home and as well in the hospital or long-term care home, if needed. Their home support workers would have the knowledge and skills to work effectively with Mr. Walters to prevent and intervene appropriately and therefore give Mrs. Walters a much-needed break. Mr. and Mrs. Walters would have the help they needed to remain in their home safely and with minimal anxiety for as long as possible. We believe that this can happen!

The System Model

Proposed Ontario Behavioural Support System Model

The Ontario BSS project is proposing an evidence-informed provincial framework and operational program model for a **cross-sectoral system** of supports and services designed to meet the needs of older adults with cognitive impairment and associated complex and challenging behaviours.

Over 400 individuals received the draft version of the key elements of the model through the Communiqué of the BSS Project and input was encouraged through a survey link. The current version includes their comments, as well as input from conversations with opinion leaders in target areas. Initial testing and evaluation of the feasibility and efficacy of this model will occur in the 2nd phase of the project. The learnings from phase 2 will inform and strengthen the final model for provincial application. Detailed information on the proposed model is available in Appendix C at www.bssproject.ca

An overarching principle is that of Person and Caregiver Centred Care

The principle of person and caregiver centred care is a key, overarching principle that must be reflected strategically as well as in day-to-day practice. All persons must be treated with respect and accepted "as one is", the older person and caregiver/family/social supports have a central voice and are the driving partners in the care and life goal decisions. Respect and trust should characterize the relationships between staff and clients and between providers across systems.

There are seven values-based principles that guide the development of health care services for people with responsive behaviours:

1. **Behaviour is Communication**: Challenging behaviours can be minimized by understanding the person and adapting the environment or care to better meet the individual's unmet needs. This principle is based on the belief that behaviours are an attempt to express distress, problem-solve or communicate unmet needs, and that most often challenging or

responsive behaviour is not meaningless, unpredictable, or only manageable through chemical or physical restraints.

2. **Respect:** All persons must be treated with respect, regardless of the situation and are accepted 'as one is', regardless of age, health status, behaviour, etc. Respect and trust should characterize the relationships between staff and clients and between providers across systems.[25] The cultural diversity of people being served requires culturally competent approaches to be effective. Practices must value the language, ethnicity, race, religion, gender, beliefs/traditions, and life experiences of the person to be relevant to the individual being served[26]; practitioners must know the person to better understand the presenting behaviours and triggers.[27]
3. **Diversity**: Practices must value language, ethnicity, race, religion, gender, beliefs/traditions and life experiences of the people being served
4. **Collaborative Care**: Accessible, comprehensive assessment and intervention requires an interdisciplinary approach, which includes professionals from different disciplines, as well as the client and family members, to cooperatively create a joint, single plan of care.
5. **Safety**: The creation of a culture of safety and well-being is promoted where older adults and families live and visit and where staff work.
6. **System Coordination and Integration:** Systems are built upon existing resources and initiatives and encourage the development of synergies among existing and new partners to ensure access to a full range of integrated services and flexible supports based on need.
7. **Accountability and Sustainability**: The accountability of the system, health and social service providers and funder to each other is defined and ensured

The proposed BSS model has three foundational pillars and each pillar includes proposed essential elements to be tested in phase 2 (see Appendix C: www.bssproject.ca)



Pillar #1 ***System Management***	**Pillar #2** ***Intersectoral Interdisciplinary Service Delivery***	**Pillar #3** ***Knowledgeable Care Team and Capacity Building***
Coordinated cross-agency, cross-sectoral collaboration and partnerships based on clearly defined roles and processes to facilitate 'seamless' care.	Interagency collaborative teams and services that bridge sectors, thereby mobilizing the right services and expertise and provide for and enable improved Transitions	(1) Strengthen capacity of current and future professionals through education and focused training to transfer new knowledge and best practice. (2) Develop skills and effective use of quality important tools and processes for continuous service improvement within and across sectors.

[25] Principles of the National Framework on Aging: A Policy Guide, Health Canada, 1998
[26] Canadian Mental Health Association, Mental Health Reform, 2010
[27] Kitwood, T.(1997). Dementia reconsidered: The person comes first. Buckingham, UK: Open University Press

Actions Designed to Move the System Forward

In this section, we will focus on the important next steps needed to create a strong Ontario wide Behavioural Support System. The time is now to move forward to take advantage of the readiness in the system and the foundational strategic investments aimed at achieving the following four system outcomes:

1) Enhanced Patient and Caregiver Experience

2) Person and caregiver-centred system

The current system is not person and caregiver driven

The caregivers are critical to the success of any changed system- both formal and informal and we need to find better ways to support them

3) Increased system efficiency

4) Equitable access to comprehensive, safe services

We need to do the work to define and measure system indicators of success

Better ways of providing care exist but the system requires some standardization of practice and the protocols to support this

Phase 2: Testing and Learning

Phase 1 has provided the foundation, in phase 2 these need to be implemented and tested and the results used to support successful spread and replication across the province. Phase 2 of the BSS project would involve testing of essential elements from each of the pillars over a two year period, observing learning and then revising based on the new understanding.

Phase 2 includes four key actions:

Action #1:	**Focused system implementation and testing of a proposed Ontario Behavioural Support System Model**
Action #2	**Coordinated evaluation, data collection and measurement**
Action #3	**Stakeholder Engagement and Knowledge Exchange**
Action #4	**Provincial Project Office**

Action #1: Focused system implementation and testing of a proposed Ontario Behavioural Support System Model

Implementation and Testing Approach

The approach to implementation and testing includes the following assumptions:

Modest new investment is required to change performance since current investments have provided a good foundation.

Many innovative solutions exist, but may not have been evaluated fully or spread across the province. Implementation must incorporate and build on these projects.

There needs to be standardization of practice through the use of guidelines and protocols in key areas

Ontario needs to continue to take a leadership role nationally on this topic

A quality improvement approach is necessary to create the system changes across all sectors and to ensure implementation includes better handoffs, integration and transitions

Knowledge exchange occurs during the implementation to facilitate spread of good ideas and ensure timely course corrections

Full coordinated evaluation is necessary including system outcomes, creation of indicators and potentially new data collection including all phase 2 projects

Pillar to be Tested	Elements	Details
#1: System Wide Implementation of BSS Model	*LHIN level testing of Full system Model*	- 2-3 Local Health Integration Networks - Chosen through a review process where they demonstrate readiness on key criteria and represent different types of LHINs - Supported by the Ontario Health Quality Council to build capacity in quality improvement, implementation and leadership - Implement a multi-year project - Work toward implementing the full system model using tools to understand their own LHIN level gaps and strengths and focusing on local system flow and handoffs
#2: Strategic LHIN Developed Interdisciplinary Intersectoral Service Delivery	*Enriched Prototype Projects*	- Capitalizing both on currently funded projects focused on this client population (e.g. Aging at Home) and on projects that could be funded by current regional divestment opportunities - Projects will be required to incorporate key aspects of BSS model and to participate in the coordinated evaluation
#3 Target Strategic Test Project	*Provincial Learning Collaborative*	- Opportunity for all stakeholders to participate in events and to act as knowledge translators - Build on Provincial Exchange and SHRTN Collaborative BSS Initiative Collab with OQHC
#4 Knowledgeable Care Terms and Capacity Delivery	*Innovation support*	- Some seed funding to support small innovations - Ensures that new ideas continue to come forward

The BSS Model includes some specific essential elements that will be included in a phase 2 testing. (For further details, see Appendix C at www.bssproject.ca) **Some examples include**

Mobile Interdisciplinary Intersectoral Seniors Behavioural Support Outreach and Transition Teams- building on currently existing outreach teams

Integrated Collaborative Intake and Referral

System Navigator/Care Coordinator

Specialized behavioural transitional treatment units

Further Ideas from the Field

Stakeholders have identified some specific ideas aimed at improving the system. Phase 2 projects will consider these ideas and build them in to their testing of the implementation of the proposed model:

Caregivers have suggested:[28]

Provide 24/7 hotline - immediate help when behaviour escalates

Provide more flexibility in respite hours- to meet the needs of caregivers

Look at ways to improve continuity of care providers both in the community and long-term care homes-fewer new faces for the patient, and more in depth knowledge for the caregiver

Teach health care workers about responsive behaviours associated with dementia

Streamline referrals- make sure they are timely and that all health care practitioners are able to make them.

Health Care Workers have suggested:

Assessments and care plans are duplicated unnecessarily and need to be streamlined and move with the patient

There is room for process improvement on the system handoffs and patient transitions

Key Opinion Leaders have suggested:

Seniors with Down's syndrome who are then diagnosed with Alzheimer's disease often pose specific challenges- could a BSS unit help to stabilize these individuals and send them to the community?

[28] See Conversations About Care, BSS Project Appendices at www.bssproject.ca

Consider innovative ways to incorporate the concept of "self management" when cognitive impairment is present

Action #2: Coordinated evaluation, data collection and measurement

A key element of phase 2 is the need for an overarching evaluation plan that addresses both funded projects currently underway as well as new projects in the focused implementation and testing of the BSS model. An Expert Advisory Group will support the evaluation and ensure integration of current knowledge and advise on an on-going data collection system. The following logic model based on the three pillars of the Ontario Behavioural Support System, will guide the evaluation framework.

Ultimate Outcomes	Person and caregiver-centred system Equitable access to comprehensive, safe services Increased system efficiency Enhanced patient and caregiver experience		
Long-Term Outcomes	• Integrate services across continuum of care • Allocate resources geographically and across continuum based on need • Increase ability to recruit and retain needed personnel	• Equitable access across Ontario • Increased patient & caregiver satisfaction	• Increase capacity of providers to manage needs of BSS population • Establish a culture of service learning and innovation
Initial Outcomes	• Increase access through greater quality of intake & transition • Increase regional accountability for care • Improve ability to identify and respond to regional performance issues • Increase job satisfaction for health workers	• Enhance inter-sectoral and inter-disciplinary care delivery • Earlier identification and intervention • Reduce caregiver distress • Increased appropriateness of services for patients • Improve access to needed services • Reduced system inefficiency (ALC days, LTCH – hospital transfers, etc.)	• Increase knowledge of current approaches to care • Attain a consistent and high quality of care
Objectives	• Create supportive transitions for clients and families • Establish formal regional networks • Implement collaborative Information & Transition functions • Implement consistent, system accountability agreements	• Clarify roles and responsibilities for care • Implement transition to 'single plan of integrated care' • Redesign and expand mobile outreach teams to enhance direct care and transitions • Transition to core coordinators and Navigators • Improve access to respite care • Realign and implement specialized treatment capacity (in hospital and LTCH)	• Build and support communities of practice/knowledge exchange • Engage with educators to support training • Promote use of standardized education materials • Adopt multiple educational approaches

System Coordination	Interdisciplinary Service Delivery	Knowledgeable Care Team and Capacity Building

An evaluation framework will:

1**) Assess the impact of the interventions** on caregivers, individuals with responsive behaviours, health care workers and the health care system

2) **Define measures of success and examine achievement** in the areas of system coordination, interdisciplinary service delivery and knowledgeable care team and capacity building (the three pillars of the BSS Model)

3) **Examine system barriers** and supports for success

4) **Utilize existing system indicators as well as defining new indicators** to meet the needs of the BSS model implementation and the target population

The following table includes some examples of indicators of interest. Some of these are currently collected and others would need to be collected with a focus on the target population in order to understand the impact of any interventions. In particular, it would be very important to gather data and understand more about the indicators highlighted in blue as they pertain to the target population.

		Relevant Pillar of BSS Model		
Ultimate Outcome	**Sample Indicators**	#1 *Systems Coordination*	#2 *Interdisciplinary Service Delivery*	#3 *Knowledgeable Care Team & Capacity Building*
Better Care **Person and caregiver-centred system** **Enhanced patient and caregiver experience** **Equitable access to comprehensive, safe services**	% of residents whose behaviours have recently worsened			
	% of LTC residents who are restrained			
	# of resident-to-resident incidents in LTC			
	% of patients connected with local outreach teams at the time of hospital discharge			
	% of patients who have all the information they need after discharge			
	satisfaction with discharge process among health care providers			
	satisfaction with discharge process among residents and caregivers			
	% of residents and caregivers who reported that they understood the discharge/transition process			

		Relevant Pillar of BSS Model		
Ultimate Outcome	**Sample Indicators**	#1 *Systems Coordination*	#2 *Interdisciplinary Service Delivery*	#3 *Knowledgeable Care Team & Capacity Building*
	% of residents and caregivers who reported that they felt supported by the discharging and/or admitting sites during the discharge/transition			
	% of caregivers reporting high caregiver stress at time of discharge/transition			
	# of health care providers who report using best practices for persons with behavioural issues			
	# of PRN medications given to manage behaviours			
Better Value **Increased System Efficiency**	Lost time and non-lost time injury rates per 100 FTEs			
	# of sick days per 100 LTC FTEs			
	Job satisfaction among health care providers			
	# of readmissions to hospital within 30 days of discharge			
	% of acute care bed days that are designated ALC			
	% of avoidable ED visits from LTC that result in hospital admission			
	Average length of stay for avoidable ED visits that result in hospital admission			
	Decreased LTC home wait times for individuals waiting for placement			
	Decreased LTC home admission refusals as a result of behaviours exhibited			
	# of avoidable ED visits per 100 LTC residents/year			

Action #3: Stakeholder Engagement and Knowledge Exchange

Webinars teleconferences, conference presentations, and strategic meetings will support stakeholder engagement and knowledge exchange both within the province and nationally. Of particular importance is the need to create opportunities to continue to hear the voices of people who are living with the challenges day to day and to ensure the ideas and experiences of the people we are trying to serve will continue to ground the work.

As well, targeted leaders will be invited to a series of working events designed to develop and evaluate tools, standards, guidelines and indicators.

Action #4: Provincial Project Office

1) Leadership for collaboration and learning- project leadership steering committee

2) Integrate and capitalize on current strategic directions and investments.

3) Centralized Project Management – provides administrative supports, coordinate communications, integrates work of multiple projects and initiatives

4) Resource management designed to provide expert guidance to the project team and to support the development of tools, protocols, guidelines and standards.

5) Support for Policy Analysis- and removal of system barriers. This is critical to the successful implementation of the BSS model, and it requires the partnership of government as well as all key stakeholders.

Some suggested activities to get started on Phase 2:

All the partners of the BSS leadership team have worked together to identify the actions required for a phase 2 and commit to work together with others in the system to make it a reality. Although modest, some funding will be required for phase 2 and this is still under consideration. In the meantime, the following activities will support the proposed actions:

System Partner	Roles, Activities
Local Health Integration Networks	Read the proposed elements of the detailed BSS model Begin to identify gaps and opportunities in the regions
MOHLTC	Start to identify policy barriers to implementation Begin to coordinate funding requests for projects for this target population Look for opportunities to integrate the phase 2 testing with other initiatives
Health Care Providers	Continue with quality improvement initiatives already started and look for ways to improve the process of care and create a care continuum Consider the BSS model when applying for funding for projects Continue with spreading the education of best practices for staff Look for opportunities to change the conversation- the system can be changed

Phase 3: Spread across the Province

Phase 2 is just the beginning. The ultimate goal is the spread of best practice and care across the province. In Phase 3, it is hoped that each person, wherever they live, will have access to supports based on the principles and model proposed in this report.

Acknowledgments

The Ontario Behavioural Support System Project – Phase 1 team includes the following individuals:

Bernie Blais**,** Chief Executive Officer, North Simcoe Muskoka Local Health Integration Network
Kenneth Deane, ADM- Health System Accountability and Performance Division, MOHLTC
David Harvey, Alzheimer Society of Ontario – *Operational Lead BSS Project*
Dr. Ken Le Clair, Regional Geriatric Psychiatry Program, Providence Care
Joy Greenleese, Representative "Lived Experience
Cheryl Faber, North Simcoe Muskoka LHIN
Tim Burns, Performance Improvement and Compliance Branch, MOHLTC
Robert Francis, Health Program Policy and Standards Branch, MOHLTC
Megan Harris, Alzheimer Knowledge Exchange
Beth Martin, Alzheimer Society of Ontario
Stella Ng, Health Program Policy and Standards Branch, MOHLTC
Angelina Yau, Mount Sinai Hospital, Toronto
Erin Hughes, Project Manager

The project team would like to acknowledge the following individuals who provided their advice and wisdom for different aspects of the content of this report.

Deanna	Abbott-McNeil	Improvement Facilitator Lead, Ontario Health Quality Council
Carl	Balcom	Senior Director, Residential Programs, Bruyère Continuing Care
Vicki	Barrow	Manager of Support Services St. Joseph's at Fleming Long Term Care
Debra	Bell	Manager of Long-Term Care and Community Care, Ontario MOHLTC
Tabatha	Bowers	Clinical Nurse Specialist, Specialized Geriatrics and General Internal Medicine
Magdalen	Carter	Director, Alzheimer Outreach Services of McCormick Home, London, ON
Shirley	Cassel	Administrator
Floydeen	Charles-Fridal	Integrated Psychogeriatric Outreach Program, Regional Municipality of York
Paulina	Chow	Vice President Long Term Care Services
Dr. Carole	Cohen	Clinical Director, Sunnybrook Health Sciences Centre
Lori	Elder	Integrated Psychogeriatric Outreach Program, Regional Municipality of York
Scott	Farraway	Peel Halton Acquired Brain Injury Services
Dr. Corrinne	Fischer	Director of Geriatric Psychiatry, St. Michael's Hospital
Wendy	Francis	Behaviour Analyst
Dr. Gary	Gerber	West Park Healthcare, Toronto
Gail	Grant	Manager, PRC, Peterborough Regional Health Centre
Penny	Hubbert	Manager Seniors Community Programs, Regional Municipality of York
Jim	Hughes	Behaviour Management Services of York & Simcoe, Richmond Hill
Dr. Elizabeth	Johnston	Medical Director Cummer Lodge

Corinne	Kagan	Ontario Neurotrauma Foundation
Dr. Ron	Keren	Clinical Director, Geriatric Psychiatry, Toronto Rehabilitation Institute
Dr. Andrea	L Moser	Physician
Dr. Carolyn	Lemsky	Community Head Injury Resource Services, Toronto
Jacqueline	Lyn	Psychogeriatric Resource Consultant
Al	McMullan	Peel Halton Acquired Brain Injury Services
Carrie	McAiney	Assistant Professor, McMaster University
Dr. Howard	Ovens	ER/ ALC Expert Panel
Eileen	Patterson	Ontario Health Quality Council
Andrea	Pomeroy	Chief Operating Officer Thomas Health Care Corp.
Dr. Laura	Rees	Ottawa Hospital/The Rehabilitation Centre, Ottawa
Tony	Schembri	PhD Psychology (Candidate), Psychogeriatric Resource Consultant
Mary	Schulz	Director, Information, Support Services and Education, Alzheimer Society of Canada
Agnes	Scott	Integrated Psychogeriatric Outreach Program, Regional Municipality of York
Lynn	Slaney	Director of Education, Preferred Health Care Services
Cathy	Szabo	Chief Executive Officer, Central Community Care Access Centre
Dr. Lisa	Van Bussel	Geriatric Psychiatrist , SJHC ,London
Dr. Diana	Velikonja	Hamilton Health Sciences, Hamilton
Marilyn	White-Campbell	Geriatric Addiction Specialist Community Outreach Programs in Addictions (COPA)
Carol	Williams	Executive Director, Peel Halton Acquired Brain Injury Services

Local Health Integration Network Leads

Julie	Girard	South West LHIN
Blair	Philippi	Waterloo Wellington LHIN
Janesca	Lewis	Central LHIN
Nazira	Jaffer	Central West LHIN
Mark	Edwards	Central West LHIN
Andrea	Demers	Toronto Central LHIN
Dawn	Maziak	Erie St. Clair LHIN
Mike	O'Shea	North East LHIN
Jim	Restall	North West LHIN
Heather	Murchison	North West LHIN
Shirley	Stewart	Hamilton, Halton, Niagara, Brant LHIN
Rick	Giajnorio	South East LHIN
Rob	Low	Mississauga Halton LHIN
Jai	Mills	Central East LHIN

Members of the Following Groups

Community Outreach Programs in Addictions
Aging and Developmental Disabilities Community of Practice
Neurological Health Charities Canada groups
Virtual Advisory Panel BSS Project

Members of the National BSS Initiative

For Further information: www.bssproject.ca