Behavioural Supports Ontario
Soutien en cas de troubles du comportement en Ontario

Behavioural Supports Ontario (BSO): Review of Qualitative Stories

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Executive Summary

Behavioural Supports Ontario (BSO) was created to meet the needs of older adults with or at risk for responsive behaviours associated with dementia, complex mental health, substance use and/or other neurological conditions. Although increasingly understood as an expression of unmet needs, responsive behaviours such as repetitive questioning, pacing, screaming, grabbing and other forms of physical expression can nevertheless impact negatively on individuals conveying them, as well as on care partners (sometimes referred to in the literature as "informal caregivers" or "family carers"), formal care providers, other clients in community and residential settings, and the health care system as a whole.

In this report we present the results of an in-depth review of 253 "qualitative stories" produced quarterly by Ontario's 14 Local Health Integration Networks (LHINs) over three years between 2015 and 2018. These reports document BSO successes at the local level. They provide rich detail not only on what was done (e.g., needs assessment, care planning, service delivery), but by whom (e.g., LTCH teams, mobile teams, care navigators), for whom (e.g., older persons with responsive behaviours, care partners, other providers), as well as impact (e.g., fewer behaviours, improved caregiver ability to continue to care, smoother transitions between care settings) and "lessons learned" (e.g., the importance of person-centred care).

Our main findings can be summarized as follows:

- Responsive behaviours are not a single, uniform phenomenon; they have many different, complex manifestations. Behaviours such as verbal and physical expressions of risk often present in combination with others such as pacing, depression, anxiety, withdrawal, and unwillingness to accept care making them inherently challenging to diagnose and manage.

- Underlying needs are similarly multifaceted and diverse. In addition to dementia, complex mental health, addictions and cognitive challenges, BSO clients often experience multiple chronic health issues (e.g., arthritis, diabetes, heart conditions) complicated by social deficits (e.g., poverty, family breakdown, social isolation) and inappropriate or ineffective health system responses (e.g., prescribing errors, inadequate pain management, long hospital stays contributing to decline).

- First contact with BSO takes place in settings across the care continuum. While many such contacts occur in LTCHs, many also occur in the community (e.g., family home, adult day program, retirement residence) and in hospitals (acute care, continuing care, psychiatric facilities). The stories suggest that earlier interventions can sustain persons with responsive behaviours and care partners at less intensive levels of care longer.

- Multifaceted teams and collaborations are hallmarks of BSO successes. In addition to engaging health care providers in settings across the care health continuum, stories point to

the vital contributions of partners such as the Alzheimer Society, community agencies, and the police. They underscore the crucial role of care partners who, in addition to providing essential day-to-day care and support to persons with responsive behaviours in the community, often continue to provide invaluable insight and support to cared-for persons and staff while in hospitals and LTCHs.

- Transitions between care settings are critical points in care journeys which, if poorly managed, can themselves contribute to escalating behaviours. Transitions typically involve movement from a lower intensity care setting (e.g., the family home) to a higher intensity setting (e.g., a hospital or LTCH). However, they may also involve a return back to an original setting (e.g., the family home, retirement residence or a LTCH) following an acute episode. Proactive assessment and planning by inter-disciplinary, inter-organizational organizational teams can smooth transitions, ensure continuity of care, and better prepare receiving organizations (e.g., LTCHs) to respond.

- Rather than identifying a single "magic bullet" or "best practice," the qualitative stories show that BSO successes often incorporate a mix of approaches at individual, organization and system levels. Here, the concept of "person-centred" care seems crucial, since approaches that work for particular individuals in particular contexts, may not work for others, or in different contexts. "Understanding the person," including individual preferences, aspirations, and cultural, language and religious experiences, is key to providing care that can improve the lives of individuals, reduce risks to others, make staff workloads more manageable, and improve staff confidence and satisfaction.

- Benefits are widely distributed. In addition to positive outcomes such as enhanced wellbeing and quality of life for individuals with responsive behaviours and care partners, BSO initiatives can produce significant benefits at organization and system levels. These include providers who are better equipped to manage responsive behaviours without compromising the care and safety of others, and the health care system which may face fewer avoidable 911 calls, ER visits, lengthy hospital stays, and crisis LTCH admissions.

- "Lessons learned" are closely aligned with the provincial BSO framework. They speak to the importance of person-centred care; family and informal caregiver engagement; managing transitions; interdisciplinary and intersectoral collaboration; and knowledge mobilization and capacity building.

We conclude with three recommendations:

Recommendation 1. Reaffirm person-centred care

A key message from the qualitative stories is that person-centred care is not a frill. Particularly

when needs and behaviours are multifaceted and chronic, "knowing the person" and creating individualized solutions that make the most effective use of available resources, is not only good for people, comprising the health care "top line," but essential for the health care "bottom line," system sustainability.

The stories also clarify that person-centred care almost always involves care partners as an integral part of the "unit of care." This unit often persists in hospitals and LTCHs where care partners continue to play a vital role. When persons with responsive behaviours cannot speak for themselves, care partners become their voice.

Recommendation 2. Strengthen the evidence base
Building and expanding the evidence base seems essential particularly in a period when policy-makers have to make increasingly tough choices between contending demands for constrained health care resources. Options include:

- Encouraging LHINs to continue to provide qualitative stories since these offer valuable "front line" perspectives on the challenges now being faced at the local level, as well as innovative approaches to addressing them.
- Adding to the stories key performance indicators (KPIs) seen by the LHINs to demonstrate impact at the local level.
- Integrating commonly occurring indicators into a "dashboard" with easy-to-understand graphics to be communicated back to the LHINs for feedback and ongoing development.

Recommendation 3. Advance knowledge mobilization and capacity building
This speaks to the importance of putting evidence and information into the hands of those who can use it to build capacity and encourage the scale and spread of successful initiatives. BSO can play an important facilitating role.

One approach is to encourage the development of formal knowledge translation and mobilization plans as an integral part of BSO activities. Other approaches include the promotion of conventional as well as novel venues for knowledge exchange.

In this connection, the needs and perspectives of care partners should not be overlooked. Care partners make essential contributions to the care of persons with responsive behaviours across the care continuum. The stories show that tailored information, education and counselling can build care partner resilience and capacity; care partners are uniquely positioned to say what knowledge is most important for them and how they would like to receive it.

Similarly, the lived experience of care recipients is increasingly acknowledged as a legitimate and valuable element of effective, person-centred care; thinking more about how knowledge and education can prepare individuals for what lies ahead, and how, in turn, their experiences can inform future care innovations, seems an important path to follow.

1.0 Introduction

Behavioural Supports Ontario (BSO) was created to meet the needs of older adults with or at risk of responsive behaviours associated with dementia, complex mental health, substance use and/or other neurological conditions. Although increasingly understood as an expression of unmet needs, responsive behaviours such as repetitive questioning, pacing, screaming, grabbing and other forms of physical expression can nevertheless impact negatively on individuals conveying them, as well as on care partners (sometimes referred to in the literature as "informal caregivers" or "family carers"), formal care providers, other clients in community and residential settings, and the health care system as a whole.[1]

This report is the second of two commissioned by BSO.

In our first report[2] we provided an introduction to BSO and its evolution. Rather than being created as a single intervention at a particular point in time, we observed that BSO evolved over almost two decades as a framework for a mix of new and existing local initiatives aimed at improving care for persons with responsive behaviours.

In this first report we also reviewed the results of evaluations documenting a range of positive outcomes associated with BSO initiatives. These included "measurable change to health service delivery culture and provider mix" and a "renewed focus on quality improvement."[3] Care teams said they were better prepared to work together and make connections to other providers. As well, lower hospitalization rates were observed for BSO target populations living in long-term care homes (LTCHs) in some regions[4] and BSO teams in LTCHs reported enhanced point-of-care education, staff assessment and management of behaviours, resulting in improved care and care outcomes.[5]

In this second report, we present the results of a complementary in-depth review of BSO "qualitative stories" produced quarterly by Ontario's 14 Local Health Integration Networks (LHINs) over a three year period between 2015 and 2018. These reports document BSO successes at the local level. In doing so they provide rich detail not only on what was done (e.g., needs assessment, care planning, service delivery), but by whom (e.g., LTCH teams, mobile teams, care navigators), for whom (e.g., older persons with responsive behaviours, care partners, other providers), as well as observed outcomes (e.g., fewer behaviours, improved

[1] Alzheimer Society, Ontario, Alzheimer Knowledge Exchange & Ontario Local Health Integration Network. Ontario Behavioural Support Systems: a framework for care. 2011. Accessed on-line, September 2018, at http://brainxchange.ca/Public/Files/Behaviour/Framework-of-Care-BSS-11X17.aspx

[2] Morton-Chang F, Williams AP. Behavioural Supports Ontario: Review of Evaluation Outcomes. Submitted to Behavioural Supports Ontario, April, 2018.

[3] Cripps D, Harvey D. Memorandum. BSO Final Evaluation Report. 2013.

[4] HayGroup. 2013. Behavioural Supports Ontario. Hay Group Final Evaluation Report.

[5] Grouchy M, Cooper N, Wong T. 2017. Implementation of Behavioural Supports Ontario (BSO): an evaluation of three models of care. Healthcare Quarterly Vol. 19, No. 4. Accessed on-line, March 2018 at https://www.oltca.com/OLTCA/Documents/Reports/ImplementationOfBSO_EvaluationOfThreeModelsOfCare_HQVol19No4.pdf

care partner ability to continue to care, smoother transitions between care settings) and "lessons learned" (e.g., the importance of "person-centred" care) to inform future initiatives.

This second report has two main objectives:

- To document the characteristics of BSO successes from the perspectives of those on the "front lines" of care
- To synthesize lessons learned to improve practice at the local level and support the spread and scale of successful initiatives across the province.

For readers who may not be familiar with our first report, we begin with a brief summary of its main findings to "set the stage" for this second report.

We then turn to our analysis of the LHIN qualitative stories. In addition to providing details of what we analyzed and how, we describe what we found in eight key areas:

- Responsive behaviours (e.g., repetitive questioning, pacing, screaming, grabbing and other forms of physical expression, anxiety, unwillingness to accept care)
- Client needs (e.g., often including combinations of cognitive *and* health *and* social needs)
- Initial point of BSO contact (e.g., family home, community program, retirement residence, hospital, LTCH)
- Involved providers (e.g., BSO outreach teams, mobile teams, BSO champions in LTCHs, family doctors, social workers, geriatric specialists, Alzheimer Societies, police services)
- Care transitions (e.g., from home to hospital, hospital to LTCH, LTCH to hospital and vice versa)
- Interventions at individual, organization and system levels (e.g., person-centred innovations such as music and doll therapy; organization-level initiatives such as staff counselling and peer support; regional-level workshops and capacity building)
- Impact at individual, organization and system levels (e.g., fewer behaviours and enhanced quality of life for clients and care partners; more knowledgeable and confident providers; avoided hospital emergency department visits and crisis placement to LTCHs)
- Lessons learned (e.g., person-centred care; caregiver and family engagement, knowledge mobilization and capacity building).

In a final section we summarize our main findings and offer three recommendations to build local capacity and promote the spread and scale of BSO successes across Ontario.

2.0 Summary of Key Findings from Our First Report

2.1 Responsive Behaviours

A first key finding was that responsive behaviours, and underlying needs, are highly diverse.

We reported that in addition to dementia, responsive behaviours may be rooted in underlying mental health issues, addictions, and neurological conditions affecting memory, judgement, orientation, mood and behaviour. They may result from changes in physical status (e.g., discomfort or pain); intellectual status (e.g., cognitive impairment); emotional condition (e.g., anxiety); personal capabilities (e.g., ability to perform routine daily tasks); the environment (e.g., noise or lighting); or the actions of others (e.g., inappropriate or insensitive care). Fear of pain, fear of falling, poor comprehension, anger, poor relationships, eagerness for greater participation in care decisions, past experience with medication errors and unacceptable care, or a desire to modify care, can all trigger responsive behaviours.

Responsive behaviors are similarly varied. While media reports tend to focus on highly visible incidents of physical expressions of risk (e.g., hitting, grabbing, biting, scratching, pushing, and throwing things), behaviours can also include less visible expressions such as anxiety, depression, withdrawal, or unwillingness to accept day-to-day care.

The effects may be widely felt. In addition to the negative impact on individuals, responsive behaviours can result in fatigue, distress and burnout for care partners; discomfort or harm for other clients and staff in adult day programs, retirement residences, hospitals and LTCHs; as well as added stress for formal providers. They may also result in 911 calls, emergency department visits, long hospital stays and crisis admissions to LTCHs. In addition, responsive behaviours can prompt refusals by providers, including LTCHs and adult day programs, to accept individuals into care, or to continue to provide care.

2.2 BSO Evolution

A second key finding was that the BSO Initiative evolved progressively as a framework for a mix of existing and new initiatives to improve care for persons with responsive behaviours in community, hospital and LTCH settings.

With its beginnings in public consultations around a provincial dementia care strategy in the late 1990s, BSO emerged in its own right following an announcement by the Ministry of Health and Long-Term Care (MoHLTC) in 2010 of an investment of $40M toward the development of "an evidence and experience-based framework to enhance the availability of supports and services to persons living with responsive behaviours."[6]

In 2011, a "principle-based" Framework of Care was developed with "three pillars" emphasizing:

[6] Behavioural Supports Ontario. Background. Accessed on-line, September 2018, at http://www.behaviouralsupportsontario.ca/29/Background/

- *System coordination and management* through "cross-agency, cross-sectional collaboration and partnerships"
- *Integrated service delivery: intersectoral and interdisciplinary* care through "outreach and cross-sector interdisciplinary transitional teams across the continuum [to] enable equitable and timely access and transitions to the right provider for the right service"
- *Knowledgeable care team and capacity building* to strengthen "the capacity of family caregivers [care partners] and professionals" and achieve "person-directed care, prevention and early detection; implementation of standardized best practices in behavioural health; and continuous quality improvement."[7]

The local character and contexts of the program were also emphasized. While building on these common principles, Local Health Integration Networks (LHINs) would implement approaches suited to local needs and resources.

By early 2012, all 14 LHINs had adopted this Framework. A Coordinating and Reporting Office (CRO) was created to ensure fiscal accountability and coordinate province-wide implementation at the LHIN level. Skills-building tools, including assessment tools that encouraged new insights into why people exhibit responsive behaviours, were developed and shared along with the dissemination of care pathways and approaches to clinical integration.

Although the CRO officially ended in 2013, its Final Implementation Report[8] highlighted successful LHIN-level approaches. These included:

- Mobile teams
- Centralized access (one number to call)
- System navigators
- Common assessment toolkits
- Integrated care teams spanning community, hospital and LTCH sectors.

In 2017, these were re-classified into six BSO "models" entailing sector-specific and sector-spanning approaches:[9]

- Embedded teams "within LTCHs (e.g., PSWs, RPNs, RNs, Recreational Therapists) that are funded to support the delivery of care for residents presenting with responsive behaviours"
- Long term care mobile teams "led by a lead organization that delivers outreach support to LTCHs throughout a region"

[7] Ontario Behavioural Support Systems: A Framework for Care. January 2011. Accessed on-line, August 2018, at http://brainxchange.ca/Public/Files/BSO/Framework-of-Care-BSS-11X17-1.aspx. See also, Behavioural Supports Ontario. Provincial Framework of Care. Accessed on-line, September 2018, at http://www.behaviouralsupportsontario.ca/25/Provincial_Framework_of_Care/

[8] Behavioural Supports Ontario. Final Implementation Report. 2013. Accessed on-line, September 2018 at http://brainxchange.ca/Public/Files/BSO/BSO_Q4-Report-FINAL-en.aspx

[9] Behavioural Supports Ontario. 2017. Behavioural Supports Ontario 14 LHIN Models Guide. 2017. Accessed on-line, September 2018 at http://hnhb.behaviouralsupportsontario.ca/Uploads/ContentDocuments/BSO%20Model%20Reference%20Guide_May2017.pdf

- Community teams "funded to support BSO patients[10] and family care partners residing in the community (including private dwellings, retirement homes, group homes, assisted living, etc.)"
- Cross-sector teams "funded to support BSO patients and care partners wherever they reside (i.e., LTC, Community, Acute Care, etc.)"
- Dedicated acute care positions, "staff or teams that support patients presenting with responsive behaviours in the acute care sector"
- Behavioural Support Units, specialized units in LTCHs that "wrap higher intensity care around residents with complex responsive behaviours."

This period also saw an increasing focus on LTCHs. In 2015, responding to the MoHLTC, the BSO Consultative Work Group[11] considered five "legacy indicators" for "ongoing monitoring" of BSO progress across the province at system and individual levels. In the end, the group recommended a single BSO legacy measure: change in behavioural symptoms among LTCH residents.

Provincial funding also increasingly concentrated on LTCHs. In 2016/17, the MoHLTC announced an added $10 million to BSO,[12] with $10 million more promised for 2017/18, bringing total program funding to $64 million (including the original $40 million investment and top-ups of $4 million); the bulk of these funds were directed to LTCHs. According to the 2017 Budget, "the Province is working towards the goal of a BSO resource in every long-term care home in Ontario." Further, all ministry-funded BSO community or hospital services were to be "aligned to the LTCH sector."[13] However, it was anticipated that LHINs would continue to provide BSO support in community and hospital settings by leveraging their own resources in addition to those soon after provided through the Ontario Dementia Strategy.

2.3 Evaluation Highlights

A third key finding concerned previous evaluation results. These results were positive overall, although focused mostly on LTCHs.

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[10] Please note this is "patient" is outdated terminology and better reflected by people living with dementia, mental health and/or substance use. Please refer to the 2019 Behavioural Supports Ontario Person Centred Language Initiative at http://brainxchange.ca/BSOPerson-Centred-Language.aspx

[11] LHIN Collaborative. Behavioural Supports Ontario (BSO) Consultative Work Group. Recommendations for the BSO Provincial. 2015.

[12] Ontario. Ontario investing additional $10 million to enhance behavioural support program. August 18 2016. Accessed on-line, August 2018, at https://news.ontario.ca/mohltc/en/2016/8/ontario-investing-additional-10-million-to-enhance-behavioural-supports-program.html

[13] Hamilton Niagara Haldimand Brant LHIN Board of Directors Meeting Materials. 2017. AC_C.1 (iii) Behavioural Supports Ontario Annual Funding Briefing Note. Page 215. Accessed on-line, March 2018, at http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwjE677k7fnZAhVNbK0KHa1pAsQQFggnMAA&url=http%3A%2F%2Fwww.hnhblhin.on.ca%2F~%2Fmedia%2Fsites%2Fhnhb%2FBoard%2520and%2520Governance%2FBoard%2520Meetings%2F2017-18%2520Meeting%2520Materials%2FBOD%2520Materials%252027Sept17.pdf%3Fla%3Den&usg=AOvVaw0_PnRSTO90gCyfdsjvwhOm

For example, an extensive 2013 evaluation conducted by the HayGroup[14] using both qualitative and quantitative methods, assessed the impact of BSO initiatives in four "early adopter" LHINs (Hamilton Niagara Haldimand Brant, Central East, South East and North Simcoe Muskoka). It found that:

- BSO initiatives facilitated timely intake and access to care, with improved quality of care in LTCHs. Training in behaviours and behavioural management was highly valued; teams felt they were better prepared to work together and make connections to other providers; and knowledge gained through the BSO initiatives was deemed valuable in building capacity to care for LTCH residents.

- Rates of acute care hospitalization for BSO target populations residing in LTCHs in early adopter LHINs were lower than in other LHINs with nominal savings of almost $5 million.

Adding to these findings, a survey of LTCHs conducted by investigators at the Ontario Long-Term Care Association (OLTCA), an industry-funded group, found that:

- Compared to LTCHs accessing support from mobile teams, homes with dedicated in-house teams were more likely to agree that BSO had enabled point-of-care education; supported staff to assess and determine individualized interventions to manage behaviours; and provided support for homes' own behavioural management programs. These homes also reported lower rates of use of physical restraints and antipsychotic drugs.[15]

3.0 Review of Qualitative Stories

3.1 What We Did

Informed by these findings, we conducted an in-depth review of the qualitative stories written quarterly by Ontario's 14 LHINs for the MoHLTC in the three year period 2015/16, 2016/17 and 2017/18. These stories document BSO successes at the local level. As such, they provide rich detail not only about what was done and why, but by whom, to whom, along with outcomes and lessons learned.

The consultants (FMC and APW), both trained and experienced qualitative researchers and evaluators, independently read and coded each of the qualitative stories to identify recurring themes and dimensions. They subsequently cross-checked their coding to identify consistencies and reconcile inconsistencies, mostly omissions, where one consultant had identified something of interest where the other had not.

[14] HayGroup. 2013. Behavioural Supports Ontario. Hay Group Final Evaluation Report.
[15] Grouchy M, Cooper N, Wong T. 2017. Implementation of Behavioural Supports Ontario (BSO): an evaluation of three models of care. Healthcare Quarterly Vol. 19, No. 4. Accessed on-line, March 2018 at https://www.oltca.com/OLTCA/Documents/Reports/ImplementationOfBSO_EvaluationOfThreeModelsOfCare_HQVol19No4.pdf

To enhance policy relevance, and strengthen the evidence base, we opted for a facts-based approach aimed at reporting details of successful initiatives. In doing this, we used the BSO Framework to inform our analysis.[16] As noted, the Framework's three pillars highlight system coordination and management; integrated service delivery – intersectoral and interdisciplinary; and knowledgeable care team and capacity building.

We identified eight key reporting dimensions:

- Responsive behaviours (e.g., verbal/physical expressions of risk, depression, refusal to accept care)
- Client needs (e.g., health and social needs)
- Initial point of BSO contact (e.g., community, hospital, LTCH)
- Involved providers (e.g., health and social care providers)
- Transitions between care sites (e.g., from community to hospital to LTCH or vice versa)
- BSO initiatives (e.g., at individual, organization or system levels)
- Outcomes and benefits (e.g., for individuals, providers, health care system)
- Lessons learned (e.g., to inform future successes).

We then compiled extensive lists of items along each of these dimensions. For example, within the first dimension, we listed behaviours such as anxiety, depression, mood changes and physical expressions of risk.

Similarly, for the second dimension, we listed BSO client health needs including dementia and co-morbidities such as cancer, diabetes, hearing and speech deficits. We also listed social deficits such as family distress, poverty and social isolation, as well as complicating system responses such as delayed/missed diagnoses, inappropriate prescribing, and lengthy hospital stays contributing to physical or mental decline.

For each of the eight reporting dimensions we provide a sample of verbatim excerpts from the qualitative stories (often including spelling and grammar errors) to provide rich insight into realities "on the ground." Each excerpt was assigned a unique identifier (corresponding to year-quarter-story number) so that it could be verified if required. To protect identities, all names (fictitious or not) were redacted. It is important to note that stories were submitted prior to the implementation of more "possibilities focused language" over "problems-based language" and may not always include BSO's current preferred terminology.[17]

[16] Behavioural Supports Ontario. Provincial Framework of Care. Accessed on-line, August 2018, at http://www.behaviouralsupportsontario.ca/25/Provincial_Framework_of_Care/. See also Ontario Behavioural Support Systems: A Framework for Care. January 2011. Accessed on-line, August 2018, at http://brainxchange.ca/Public/Files/BSO/Framework-of-Care-BSS-11X17-1.aspx

[17] Behavioural Supports Ontario Person Centred Language Initiative. Accessed on-line, June 2019, at http://brainxchange.ca/BSO-Person-Centred-Language-Initiative.aspx

3.2 What We Found

As noted, both consultants read and coded all qualitative stories submitted quarterly by Ontario's 14 LHINs in the three year period 2015/16 to 2017/18. Since some LHINs provided more than one story in a quarter, while others did not provide a story every quarter, numbers vary across reporting periods. In total, 253 qualitative stories were submitted by the LHINs.

Year & Quarter	Number of Qualitative Stories
2015/16 Q1	18
2015/16 Q2	15
2015/16 Q3	22
2015/16 Q4	22
	77
2016/17 Q1	23
2016/17 Q2	21
2016/17 Q3	19
2016/17 Q4	25
	88
2017/18 Q1	22
2017/18 Q2	25
2017/18 Q3	16
2017/18 Q4	25
	88
Total	**253**

3.2.1 Responsive Behaviours

Elaborating what we observed in our first report, the qualitative stories reveal that responsive behaviours have many different, often complex manifestations.

Some, like depression and withdrawal, may impact primarily on the individuals expressing them, eroding wellbeing and quickening physical and mental decline. In comparison, behaviours like verbal and physical expressions of risk can pose serious risks to self and others including family members, other clients and care providers.

We compiled an extensive list (in alphabetical order) of reported behaviours, noting that in some cases (e.g., alcohol/tobacco/substance use) it was not clear whether these were seen as the behaviours to be addressed, or factors contributing to them. Reported behaviors include:

- Alcohol/tobacco/substance abuse
- Anxiety
- Collecting/hoarding
- Crying/sobbing
- Depression

- Exit seeking
- Fear
- Hallucinations
- Hearing voices
- Incontinence
- Isolation
- Mood changes
- Pacing
- Paranoia
- Physical expression of risk/striking out/hitting/biting/kicking/throwing/choking
- Perseveration (e.g., persistent repetition of words, questions, responses or movements)
- Poor impulse control
- Resident-on-resident conflict
- Resistance or unwillingness to accept care (e.g., meals, medications, personal hygiene)
- Restlessness
- Self-neglect
- Sexual touching/inappropriate sexual comments
- Spitting
- Verbal expression of risk/yelling/swearing
- Wandering/"exploring"
- Withdrawal.

As might be expected, behaviours are a common starting point for the qualitative stories. For instance, stories describe individuals as:

- Showing an "increase in responsive behaviours (exit seeking, resistance to care, verbal expressions, and excessive pacing)" (16-3-01)
- Being "physically responsive causing injury to staff while they assisted with care" (16-3-18)
- Presenting with "increased confusion, paranoia, and odd behaviour as she would look for her friend in the fridge and was seeing her dead husband in her bed" (17-1-03)
- Displaying "restlessness and eating/drinking inappropriate substances"(18-1-09)
- Often crying "uncontrollably, and was thought to be delusional and hallucinating" (18-2-08).

The stories also emphasize that even at the point of first contact with BSO, behaviours are often complex. For example:

- A female LTCH resident "was prone to hoarding; several blankets in her bed, stacks of newspapers books all over. There were spoons hidden in towels & under pillows. Her night table was full of various garbage items. The room had a very foul smell, and the resident was constantly soiled. The resident was also resistant to having anyone enter her room or

help her with "chores". She would "wash" her clothes in the sink & leave them there, creating more mess and odour. She would also refuse meds, deny care and rarely left her room for meals, housekeeping or to join any of the programs available." (16-4-11)

- In addition to "inappropriate sexual comments to female care providers," a male LTCH resident "had punched PSWs several times and spit in their faces." He also proved unmanageable during showers" requiring up to four staff in attendance. (17-1-12)

- A community-dwelling male was referred to a BSO Team as "the police were being called on a regular basis by members of the community including the local community centre; the Mental Health Impact team working with police were requested to support police; community centre staff expressed concern for safety of their community members which include children. The community centre issued a no trespassing order to the client in response to client smoking in non-smoking designated areas and publically urinating outside the centre." (17-3-05)

- A female LTCH resident was referred for "repetitive questions about death, eating non-edibles, throwing self on floor, and for pinching, scratching, biting, grabbing co-residents, family members, visitors and staff." (18-1-12)

- A male LTCH resident "was observed to moan, shout or yell out in Portuguese around the clock … Increase[d] levels of agitation, irritability, and bouts of confusion; Refused medication, food, care. Demonstrated by kicking, grabbing and hitting staff on each care approach; swears at staff in Portuguese with auditory hallucinations and delusions." (18-3-09)

3.2.2 Client Needs

The qualitative stories provide a similarly extensive list of needs underlying responsive behaviours.

Although not always stated explicitly, clients described in the stories appear to fall into BSO target populations: they have needs related to dementia, cognitive deficits, and/or mental health problems and addictions.

Moreover, many clients experience these needs in combination with:

- Health co-morbidities (e.g., cancer, arthritis, heart disease)
- Social deficits (e.g., poverty, family distress, social isolation)

- Complicating health system responses (e.g., inappropriate prescribing, failure to diagnose and treat conditions such as chronic pain, and/or lengthy hospital stays contributing to mental and physical decline).

For the most part, it remains unclear which came first: whether, for example, social determinants of health such as poverty contributed to substance use, or vice versa, in turn contributing to health problems such as heart disease, resulting in lengthy hospital stays or crisis LTCH admissions, further complicating responsive behaviours.

What is clear is that at the time individuals make first contact with BSO, whether in the community, in a hospital, or in a LTCH, most experience complex combinations of needs contributing to similarly complex behaviours.

Health-related needs reported in the stories (listed below in alphabetical order) include:

- Acquired brain injury (ABI)
- Addictions withdrawal
- Alcohol use/excessive drinking
- Anxiety disorder/panic attacks
- Apathy
- Aphasia
- Arthritis/rheumatoid arthritis/osteoarthritis
- Autism
- Basal carcinoma
- Breast cancer
- Cancer
- Cerebrovascular accident (CVA)
- Cognitive delays
- Confusion
- COPD
- Coronary artery disease
- Constipation
- Delirium
- Dementia
- Developmental delay
- Diabetes
- Drug dependence
- Dyslipidemia
- Epilepsy
- Failure to thrive
- Hallucinations

- Hearing and speech deficits
- Hemiplegia
- Hypertension
- Hyperthyroidism
- Hyperglycemia
- Incontinence
- Joint replacements/complications
- Korsakoff syndrome
- Mobility challenges
- Mood disorder
- Pain/chronic pain
- Paranoia
- Raynaud's disease
- Seizures
- Skin irritations
- Sleep issues
- Spinal stenosis/injuries
- Stroke
- Tobacco use
- Urinary tract/bladder infections.

Social needs include:

- Caregiver burnout/compassion fatigue/unwillingness or inability to continue to provide care
- Criminal activity/convictions
- Domestic abuse/assault/violence
- Family distress/breakdown
- Home accessibility issues (e.g., a long, steep staircase)
- Homelessness
- Poverty/financial stress
- Self-neglect
- Social isolation.

Complicating system responses include:

- Crisis admissions to LTCHs away from family and social support networks
- Delayed/missed diagnosis (e.g., chronic pain, UTIs)
- Difficult-to-access primary care and community-based supports
- Inadequate knowledge on the part of health care providers around diagnosis and management of responsive behaviours

- Inadequate pain management
- Inappropriate prescribing/polypharmacy
- Lack of culturally appropriate care
- Lengthy hospital stays contributing to physical and mental decline
- Provider unwillingness to accept individuals with responsive behaviours into care or to continue to provide care.

Excerpts from the qualitative stories illustrate how dementia, cognitive deficits and mental health and addictions drive BSO referrals. For example, stories describe clients as having:

- "Lewy Body Dementia and Parkinson's Disease" (16-2-03)
- "Korsekoff's Dementia" (16-4-01)
- "Diagnosis of Frontotemporal Dementia" (17-3-05)
- "Late stage dementia" (18-2-07)
- "Acute mental health distress." (18-4-01)

The stories also emphasize that most individuals present with complex health and social needs, sometimes complicated by inappropriate or ineffective system responses.

- A female "had been living at a retirement home (for approximately 13 months) and by all reports was high functioning and oriented and participated in all her ADLS. In November she was prescribed Trazadone to assist with her sleep issues. Within 6 days of starting the medication, the resident had locked herself in her closet and became confused and experienced notable mood changes." (16-3-01)

- In addition to "cognitive delays" and dementia, a community-dwelling male had had a stroke, experienced "significant financial stressors" and was under a probation order following "bouts of uncontrolled anger and assaults on family members." (17-1-04)

- "[Female] 74 with recent CVA had two failed discharges from hospital into the community. Dealing with new physical impairments from a stroke 3 months earlier, exacerbated a chain of events leading to re-hospitalization from depression, delirium from a raging bladder infection, seizures and diagnosis of vascular dementia. This resulted in behaviours due to sleep deprivation and inadequate pain management. [She] cried out for many hours in the day and night. This contributed to other residents in her first community setting to exhibit behaviours towards her." (17-2-9)

- "A 53 female resident was admitted from a local hospital to [LTCH]. The resident had an acute stroke in January 2015 causing aphasia, hemiplegia and was on G-feed and catheter. She also has vascular dementia, chronic depression, history of alcohol abuse, hypertension, dyslipidemia, diabetes, and osteoarthritis. Resident is divorced and also a victim of domestic

abuse. She had a restraining order for her former spouse. Resident lived with three children before having CVA. One son has autism" (17-4-14)

- "The BSO Clinical Leader noted that [the resident] had received large amounts of medication on an "as-needed" basis, which actually contributed to her responsive behaviours." (18-1-08)

3.2.3 Initial Point of BSO Contact

The "three pillars" of the BSO Framework highlight system coordination and management; integrated service delivery – intersectoral and interdisciplinary; and knowledgeable care team and capacity building. These pillars anticipate that care will be provided in settings "across the continuum" to ensure "equitable and timely access to the right provider for the right services."[18]

The qualitative stories confirm that while many BSO successes occur in LTCHs, others take place in community and hospital settings.

In many cases, BSO efforts in community and hospital settings are *preventative*, aimed at avoiding an escalation in behaviours which could erode wellbeing and independence, result in caregiver burnout, or precipitate an emergency department visit, hospital admission, or crisis LTCH placement. For example, stories talk about efforts by community-based teams to maintain individuals with responsive behaviours in a familiar setting for as long as possible.

In other cases, efforts are *restorative*, aimed at allowing individuals to return back to a familiar care setting as quickly as possible. For example, stories speak to cases in which staff of a retirement residence or LTCH feel they are no longer able to provide appropriate care while maintaining the safety and security of other residents, leading to a hospital admission, and/or refusal to re-admit. BSO hospital teams, in collaboration with family and other providers, then work to assess needs, develop individualized care plans, and educate and support care partners and staff, leading to a successful return to the original care setting.

The qualitative stories demonstrate that first contact with BSO occurs in settings across the care continuum including:

- Home and community (e.g., family home, adult day program, retirement residence, supportive housing)
- Hospital (e.g., acute care/continuing care/psychiatric facility)
- LTCH

[18] Ontario Behavioural Support Systems: A Framework for Care. January 2011. Accessed on-line, September 2018, at http://brainxchange.ca/Public/Files/BSO/Framework-of-Care-BSS-11X17-1.aspx

Stories beginning in the *community* include:

- "A 74 yr. old female client who started the Adult Day program in April of 2013 with diagnosis of dementia … Upon admission, she [had] a mild case of dementia and able to perform ADL's and do the cooking, shopping with spouse and be on her own. One year later, she was admitted to our dementia program as there had been significant deterioration and was not functioning well in the existing program. She was unable to help spouse with household duties, fearfulness of being alone, repetition of sentences, high energy, refusal to eat, anxious, crying episodes, depression and fixated on stomach pains and restless nights." (16-1-03)

- "95 year old man, diagnosed with moderate Alzheimer's Dementia, living alone in the community in his own home. Supported by two daughters (out of town) who visited each weekend to provide support. A supportive tenant also living in basement apartment. CCAC involved for PSW supports daily to assist with meal cuing and hygiene and for LTC application. Increasing concerns for client's well-being due to functional decline, safety concerns, and overall vulnerability within the community. Client would often call family multiple times in the day anxious or confused." (16-3-06)

- "[She] was an 82- year-old lady living with her spouse in a medium-sized city. Her children … lived nearby. In 2016, [she] began leaving her home and walking down the street alone without regarding traffic safety rules. When her family caught up with her to bring her home, [she] would state that she was in Malaysia, and needed to run errands. The family responded by trying to change [her] thinking, telling her that she was in Canada and did not need to complete any errands. However, this response caused [her] to become more upset. Feeling overwhelmed and concerned for their mother's safety, [the children] visited various organizations in their city trying to find support." (17-2-07)

- "A regional police service received phone calls from several community members, stating that their neighbour, [an older male], seemed 'confused'. They reported that [he] was walking outside in the wintertime, approaching neighbours to ask if they could help him find his car. The police service made a referral to the Behavioural Supports Ontario Community Outreach Team (BSO COT), who quickly visited [him] at home. … The BSO COT found that [he] lived alone in a large home with a long, steep staircase – [He] reported that the stairs were becoming increasingly difficult to manage." (17-4-06)

- "70+ y.o. male with FTD residing alone in a condo with regular visits from family members. One family member was found to be engaging in criminal activity and thereby endangering the client … Client's care needs were maintained in the home until such time that removing client to safety was required. Client was attending the Day Program and was accommodated for some weeks at the Overnight Stay program while alternative arrangements were organized." (18-1-06)

Stories beginning in a *hospital* include:

- "Due to an increase in risk to self and others, and potential delirium, client was … admitted to hospital for treatment … Client endured several transitions throughout the hospital due to unmet medical and psychiatric needs. CCAC BSO Care Coordinator followed the client during all of these transitions, communicating BSO interventions to the various staff members on each unit. CCAC BSO Care Coordinator also implemented behavioural tracking … Due to client's length of stay at hospital exceeding LTCH policy, client was discharged from LTCH …" (16-4-02)

- "An 84-year old man with diagnosis of dementia had been admitted to a specialized in-patient assessment and treatment unit from his home in the community due to an inability to manage independently. He had been on the unit for 8 months and due to the responsive behaviours identified by the hospital staff, his application to LTCH had been refused by quite a few LTCHs." (17-4-05)

- "[He] was an older gentleman who was brought to hospital by police. The police reported that [he] had attempted to strangle his spouse, hit her, bit her, and chased her around their home. [He] was admitted into the mental health unit under a Form 1. This was the third episode of physical responsiveness in approximately one year. Upon admission, [his] spouse and family told the care team that they could no longer support him in the community, and they felt that he should move into a long-term care home." (17-4-07)

- "I met M at the hospital where she had an extended stay for over 2 months. She was admitted with concerns of hyperglycemia and query alcohol withdrawal. Her sons told me, there is long standing history of anxiety disorder and she would have a glass of wine but her alcohol consumption has been likely on the increase lately. One of sons N lives with her. Her sons told me that M was seeing a 'specialist' psychiatrist or psychologist in the past, but they didn't really know 'why' at some point she just stopped going to this specialist maybe she thought it wasn't helping her." (18-2-08)

- "Walter was an older gentleman who had been in the hospital for approximately 20 months. He had lived in an apartment before his admission to hospital, but his physical and cognitive conditions had changed and his care team recommended that he move to a Long-Term Care (LTC) home. Walter demonstrated some current and past responsive behaviours that posed a barrier to his acceptance into LTC, including verbal responsiveness, refusing personal care, and frequently leaving the hospital to smoke cigarettes." (18-4-08)

Stories beginning in a *LTCH* include:

- "Upon admission, this resident was described as "quite difficult for LTCH staff to manage". The resident was living with complex mental health needs including major depressive disorder, schizophrenia, and personality disorder and subsequently had responsive behaviour including resistance to care, refusal of medication, and verbally responsive

behaviours." (16-2-12)

- "Client is a 71 year old female who transitioned into LTC due to an increase in responsive behaviours and hallucinations - Client is prone to Urinary Tract Infections (UTI) - Client has been diagnosed with Dementia, visual and auditory hallucinations, COPD, and chronic back pain … client endured several transitions throughout the hospital due to unmet medical and psychiatric needs …" (16-4-02)

- "BSO received first referral for client who had recently transitioned to LTC in June 2014. The environment was not conducive to client's needs. She was a very private person throughout her life and now had to share a room where residents sharing a room could quite literally touch one another from their beds. … Resources had to be pulled together to determine client's eligibility to move to a private room at another home." (17-2-01)

- "Resident not participating in social or creative programming in their LTCH setting due to barriers resulting from responsive behaviours. Resident would become agitated quickly and was often seen as disruptive in the group activity environment. Although he expressed interest in participating, he often did not tolerate the group environment well, resulting in his own escalation of behaviour and potentially triggering behaviour in others." (17-4-01)

- "Our resident, came to us as a crisis placement from the community. She had already been declined at other homes due to [issues with] exit-seeking behaviour and high elopement risk. In addition to those behaviours, she also barely slept and disrobed frequently. She was previously in another LTCH from which her family had brought her back home. They were at their limits when it came to coping with these behaviours at home. Her husband was even hospitalized during a community home visit." (18-2-17)

3.2.4 Involved Providers

The BSO "three pillars" clarify that in addition to taking place in settings across the care continuum, initiatives will engage providers in different organizations and sectors with different skills and knowledge sets through "cross-agency, cross-sector collaboration and partnerships" and "knowledgeable care team." [19]

While the extent of joint working varies extensively, the qualitative stories show that collaborations and teamwork between formal providers take place within specific organizations or care settings (e.g., in hospital or LTCH) and across organizations and settings (e.g., a community team working with a hospital team and/or a LTCH team).

Multifaceted teams respond to the complexity of client needs and behaviours. They span a wide breadth of professions, occupations, organizations and sectors, within and beyond health

[19] Ontario Behavioural Support Systems: A Framework for Care. January 2011. Accessed on-line, September 2018, at http://brainxchange.ca/Public/Files/BSO/Framework-of-Care-BSS-11X17-1.aspx

care (including police services, Alzheimer societies and faith organizations). Some are formally designated as BSO, while others join in BSO work on a consulting or as-needed basis. Further, it is clear from the stories that these collaborations can show great adaptability by "morphing" to include new skills and knowledge as needs, behaviours or care settings change.

Further, some teams and collaborations are attached to specific care settings (e.g., LTCH or hospital-based teams) while others (e.g., mobile or regional teams) work across different settings. Moreover, teams with different attachments (e.g., a hospital team and a LTCH team) will often work together especially during transitions.

The qualitative stories also emphasize that care partners (e.g., family, friends and neighbours), while not officially part of formal care teams, play an essential role in many successes. Confirming what a growing weight of international evidence shows,[20] the stories document the often extensive, ongoing efforts by care partners to support individuals with responsive behaviours in community settings. In addition to facing 24/7 demands for emotional, personal and instrumental support, many also face serious risks associated with verbal and physical expressions of risk, compounded by a lack of personal resources, and uncertainty about how to get formal help from when needed. When care partners can no longer manage, emergency hospital admissions or crisis placement to a LTCH may be a last resort.

Further, the stories clarify that even when cared-for persons move outside of the home, the care partner role does not end. The ability and willingness of care partners to provide insight into the needs, behaviours and preferences of hospitalized patients, and their willingness to receive them back into the home, are essential for effective assessment, care planning and discharge.

Likewise, even following LTCH placement, many care partners continue to make critical contributions to assessment, planning and care delivery, as well as providing direct emotional and personal care, particularly when staff resources are stretched thin. In a number of stories, the withdrawal of care partners, either as a result of a crisis placement to a geographically distant care home, or as a result of a move by care partners themselves, is identified as the trigger for escalating behaviours.

Formal providers collaborating within and across organizations and sectors in the qualitative stories include (in alphabetical order):

- Adult Day Programs
- Aging Well Clinics
- Alzheimer Societies
- BSO Crisis Mental Health Nurse

[20] Williams AP, Peckham A, Watkins J, et al., Caring for Caregivers: facing up to tough challenges. Healthcare Quarterly, October, 2014. See also, Williams AP, Peckham A, Kuluski K et al., Caring for Caregivers: challenging the assumptions. Invited Essay. HealthcarePapers vol. 15, no. 1, 2015.

- BSO Hospital Teams
- BSO Mobile Support Teams
- BSO Outreach Teams
- BSO Regional Coordinators
- BSO System Navigators
- "Care of the Elderly" Physicians
- Centre for Addiction and Mental Health (CAMH)
- Community Care Access Centres (CCAC)
- Community Living and Developmental Services Ontario
- Community Mental Health Associations
- Community mental health workers/community psychiatry
- Community Support Services (CSS) agencies (including adult day programs, respite providers and home support personal support workers)
- Court Support Workers
- Dietary, housekeeping and laundry staff
- Faith organizations (e.g., local churches)
- Family doctors
- Geriatric Addictions Specialists
- Geriatric Emergency Medicine (GEM) Nurses
- Geriatric Medicine Outreach Teams (GMOT)
- Geriatric Mental Health Outreach Teams (GMHOT)
- Hospital Neuropsychiatry Units
- LTCH Leads or Champions
- LTCH Medical Directors
- Memory clinics
- Occupational Therapists
- Office of the Public Guardian and Trustee
- Physical Therapists
- Probation Officers
- Psychiatric Intensive Care Units
- Psychogeriatric Resource Consultants
- Police services
- Seniors Mental Health Outreach services
- Social workers
- Supportive Housing Providers
- Specialized Geriatric Services
- Volunteer groups and organizations.

Stories involving collaborations and teamwork *within a single care setting* include:

- "Mr. M was admitted into … a Long-Term Care Home (LTCH) after living with his wife in a retirement home … His responsive behaviours upon admission were: wandering halls and rooms, resistive to care physically aggressive, banging utensils/bowls when meals finished and voiding in the halls. … The family provided history, favourite pastimes and successful intervention suggestions. A whole home approach together with the family input resulted in the development of multi-pronged intervention strategies. … Care team collaboration examples: Laundry staff give Mr. M a basket of towels to fold; Housekeeping provides Mr. M a broom to sweep or a cloth to dry tables; Dietary staff are able to recognize an increase in restless behaviour and provide meal prior to escalation; Mr. M's family provided an iPod for music therapy; PSWs are able to recognize toileting cues and respond quickly prior to agitation." (16-1-12)

- "A female resident moved into a LTCH from a local hospital. Prior to this she had been admitted to another hospital after being found wandering the street at which point she was diagnosed with dementia with failure to thrive. She had no family or friends and was living independently in her apartment. … Staff were instructed to redirect the resident whenever she was seen exit seeking and a Wanderguard bracelet was applied. The resident was introduced to another resident who spoke her language and a friendship developed. The resident was encouraged to assist staff in preparing the dining room for meals. Magazines in her native tongue were provided as she enjoys reading. She receives 1:1 BSO team visits where she is encouraged to verbalize her feelings, experiences and concerns on a weekly basis." (17-1-11)

- " … the in-house BSO leads recruitment, onboarding and education …The BSO in-house lead together with the Behaviour Support Resource Team have developed a brochure detailing the new initiative, purpose, roles, responsibilities, referral pathways, and other relevant information needed to introduce this resource to the rest of the LTC home. The brochure was presented at the general staff meeting." (17-4-11)

- "… the BSO Clinical Leader assisted in creating a 3-hour, interactive education session. … 56 multidisciplinary team members attended. … This education was put into action to support a [female] patient … [she] became verbally and physically responsive when staff attempted to provide her with care. She had several falls, and was administered medication in attempts to settle her behaviour. … The BSO Clinical Leader was asked to see [her] to devise strategies around her behaviours … staff on the unit felt empowered and supported in caring for [her] …" (18-1-08)

- "The BSS team initiated their assessment with observations and clinical assessments in order to assist with identifying any possible triggers. Through this process the team was

able to identify the following triggers; attempts at personal care before the resident had enough time to wake, the provision of personal care, exposure of skin (especially lower extremities), feeling cold, bathing, toileting, cognitive decline and a language barrier. There was a documented history of a past traumatic experience with sexual assault.
The BSS team in collaboration with the LTCH staff trialed strategies to assist with reducing the level of anxiety experienced by Resident during care. … The team worked with the family and a photo album to distract Resident when assisting her to tub room was put in place." (18-3-15)

Stories featuring collaboration and teamwork across *multiple care settings* include:

- "It was agreed that in order to provide optimum support to client and his spouse, a case conference would be arranged at the day program which would involve the CCAC CC, BSO team (PRC, Counsellor, CSW), ADP Supervisor, & Clients Spouse and family. It was agreed that the PRC would come into the program to work with the day program staff and CSW to devise some non-pharmacological interventions to implement with client both at the program and potentially at home. The BSO Counsellor would reach out again to client spouse to offer support." (16-2-06)

- "The Alzheimer Society … received a referral from a local Family Health Team for a 62 year old male with cognitive delays who lived at home with his wife and four adult children. … There were multiple community agencies involved with this resident, which included: Community Living (for the adult children), a Probation Officer, a Court Support Worker, a Social Worker from CCAC (assisting with the financial issues) and a worker from the Community Mental Health Association and the CCAC. … The Alzheimer's Society Support Counsellor worked with the family on education and support and as the one year timeline approached, the family wanted to reconcile. This required additional support and a referral was made to the local mobile BSO team." (17-1-04)

- "The Behavioural Supports Ontario (BSO) Clinical Leader became involved with [a female client] and recognized the need to bring together the multiple stakeholders involved in [her] care, including: Geriatrics, Psychiatry, the Crisis Outreach and Support Team, Therapeutic Recreation, Social Work, the Community Care Access Centre, and the BSO Clinical Leader. From the team meeting, the BSO Clinical Leader created a 'contract' for [her] in collaboration with the hospital team." (17-3-07)

- "The [regional] BSO staff, the ADP [adult day program] staff and the clients family collaboratively came together to establish interventions that were specific to the client needs and that would work for both at home and the ADP … Family meetings were held at key points of transition. These meetings provided an opportunity for family to share their

concerns, challenges, and feelings about the present situation. CRBT [Community Responsive Behavioural Team] was able to validate feelings and concerns, discuss care options available within the health system, and review how supports might be adapted to the unique needs of the individual and their family." (17-4-08)

- "When bed offer to Long Term Care facility was imminent, the team including client's spouse and children, family physician, LHIN Home and Community Care Coordinator, SGS Nurse Practitioner and Community Responsive Behaviour Team as well as geriatrician met to strategize how to get client successfully and safely to LTC." (18-3-05)

3.2.5 Transitions

The qualitative stories document many successful transitions between care settings including the family home, community-based programs (e.g., supportive housing, adult day programs, retirement residences), hospitals and LTCHs.

As might be expected, many transitions involve movement out of the home or other community setting, to hospitals and/or LTCHs providing a higher level of care. For example, a transition to a hospital or LTCH may occur when needs and behaviours progress to the point that they can no longer be supported appropriately and safely at home.

However, the stories show that transitions may also occur in other directions. For example, a hospitalized patient may be successfully returned home following efforts by BSO teams to establish care plans that sustain cared-for individuals *and* care partners. In other cases, interventions by hospital BSO teams may allow individuals previously refused admission to a LTCH, or discharged from a LTCH because of escalating behaviours, to be admitted to a LTCH, or re-admitted to the LTCH where they had previously resided.

Regardless of the direction, the stories emphasize that transitions almost always pose challenges and risks for cared-for individuals, care partners and formal care providers. For cared-for individuals, the stories show how a transition from a familiar place can result in disorientation, anxiety, fear, loss, withdrawal, an unwillingness to accept care, as well as verbal and physical expression of risk. For care partners, feelings of failure, guilt, shame and failure can follow the departure of a family member or friend. For formal care providers, the arrival of a new patient in hospital or resident to LTCH with responsive behaviours almost always requires significant time, effort and expertise to assess, plan and deliver individualized care while keeping in mind the needs and security of other patients/residents and staff.

In at least some cases, transfers can be avoided. Stories suggest that timely interventions whether in home and community, in a retirement residence or in a LTCH, can help to address behaviours in-place, avoiding or delaying movement to another care setting. In addition to mitigating risks for individuals, averted transfers can yield benefits for the health care system

by maintaining them at a less intensive level of care.

Stories with *no transitions* or an *avoided transition* include:

- "The restorative/behavioural dining room commenced on November 17 2014. First, we put together a committee with representatives from the following departments Nursing, Family, Social Worker, Dietary, PT, Activities and Housekeeping. The restorative/ behavioural program was piloted on a unit where there are 60 residents and about 60-70% of residents display responsive behaviours overall. … Residents would wander away from their tables; disturb other residents eating their meals and move items. They would often display verbal/physical behaviours putting others at risk. … The restorative/behavioral dining room is a smaller environment with fewer residents and less distractions and triggers. … There has been fewer documented responsive behavior episodes displayed in both the main and restorative/behavioral dining room. " (16-02-05)

- "Meet [an older male], one of our participants in the Adult Day Services program. Weeks earlier the team experienced inappropriate verbal and sexual behaviours towards other participants in the program … BSO lead for the Adult Day Services program, organized her multidisciplinary team to support [him] in a collaborative way in order to address his pain issues by using three assessment tools: PIECES, MMSE (memory assessment) and the PAINAD to address his pain from a recent wound. As an RPN, [she] recognized [the participant's] escalation in behaviour occurred in the early afternoon. Engaging the family physician, the Substitute Decision Maker for [the client] and other members of the care team resulted in effective pain management options that were safe and effective." (17-1-08)

- "Resident Y.R.S was referred to LTC BSOT for repetitive question regarding when the next meal was as well as frequent toileting request. Upon assessment staff reported feeling frustrated as the resident asked as much as "50 times a shift" when the next meal was as well as "constantly asked to be toileted". … BSOT PSW was assigned to the case to observe the resident. The RN also spoke with the resident's family to get a better understanding of what the resident was like prior to developing dementia and what her hobbies and likes included. … The RN and PSW collaborated and discussed possible strategies to help manage resident's boredom and short term memory difficulties." (17-3-10)

- "[She] was a 61-year-old lady living in Long-Term Care (LTC). [She] demonstrated verbally responsive behaviours, particularly toward two of her co-residents. …The BSO LTC Mobile Team reviewed [her] background, and learned that she had a diagnosis of frontal lobe dementia, arthritis, a brain injury since birth, and previous substance misuse. … the BSO LTC Mobile Team collaborated with nursing, personal support, therapeutic recreation, social

work, physiotherapy, Seniors Mental Health Outreach, a Psychogeriatric Resource Consultant, Developmental Services Ontario, and the home's Director of Care … By collaborating with team members with varied expertise, staff from both BSO and the LTC home were able to gain new tools and resources that will enable them to support residents in the future who have needs similar to [hers]." (18-1-07)

- "… the BSOT RN did an initial assessment and shared with the home educator detailed shower steps and strategies that she can try out for the next morning's shower. … The BSOT PSW in both day and evening observed the resident for a few days and assisted staff in providing her care and shower; they found more triggers and strategies and shared them with the home staff and BSOT RN. A behavior care plan that aims for managing resident's care, shower and agitation was then tailored by the BSOT RN and discussed with the home D and E staff in the initial behavior care plan meeting with the DOC in presence. … The BSOT RN coordinated with the DOC and educator for the time, shifts, and who needs to be coached. On the day of coaching, the educator facilitated a meeting for BSOT PSW to share the care and shower strategies with both D and E staff to help disseminate the care plan again. … mutual collaboration from both home and BSOT team and great support by the home management." (18-4-14)

Stories documenting *one or more transitions* include:

- "[A female] had 4 trips to hospital because of responsive behaviours. Each time, she was discharged back to her LTC home within a few hours or days, only to have her behaviour re-emerge. Staff at [her] LTC home worked to support her by making referrals to the Seniors Mental Health Outreach Team, the BSO LTC Mobile Team, and by consulting the in-house physician. Multiple medication changes were made and behavioural interventions were implemented, but [her] responsive behaviours continued. Feeling unable to meet her needs, staff at the LTC home again transferred her to the hospital, where a referral to the BSO Hospital Clinical Leader was made. … [Her] LTC home agreed to accept her back and to use the strategies that successfully addressed her responsive behaviours while in hospital. [She] was transitioned back to her LTC home with the BSO LTC Mobile team supporting her and the staff by teaching the strategies implemented in the hospital." (16-1-05)

- "A referral was then made to the Behavioural Supports Ontario Clinical Leader (BSO CL). The BSO CL read the patient's hospital chart, spoke with him, family, and hospital staff, and observed various people interacting with Mr. A to learn more about him as a person, and his responsive behaviours. … hospital staff and the BSO CL soon felt that Mr. A's needs would no longer be best met in an inpatient behavioural health assessment program. An application was submitted to long-term care (LTC) and Mr. A was soon offered a bed in a home that he and his family had chosen. … The BSO CL provided a 'warm hand-off', including a thorough update of Mr. A's situation to the BSO LTC Mobile Team to support Mr.

A's transition into the LTC home … Two members of the team were present at Mr. A's LTC home on the day he arrived to ensure he and his family felt comfortable with the transition, and pass along the effective strategies to staff at the home." (16-2-04)

- "The [CCAC] received a referral for the Regional Behavioural Support Unit …from a Supportive Housing [SH] facility … for one of their residents who was spitting, shredding papers and hoarding with episodes of verbal aggression. … Strategies were provided by the psychiatry team but proved to be unsuccessful in the supportive housing environment. Eligibility to the behavioral unit was determined … and the resident was admitted to the unit … [with collaboration between] the … System Navigator … the [SH] facility, community psychiatry, the Psychogeriatric Resource Consultant (PRC) and the RBHSU in preparation for admission. … [The] System Navigator met with the resident and family as well providing education regarding responsive behaviors and preparing the resident and family for admission to the unit. … Getting a good history of the resident, accessing community supports and working with the resident on the unit from a pharmacological/non-pharmacological perspective resulted in a successful discharge in December of the same year … to a LTCH of her choice. … My client was not sent to the hospital to take up an acute care bed... " (16-3-21)

- "[An older female] lived in a Retirement Home, where she spent her time socializing with her family and caring for her dog. …. It was found that she required more assistance than could be provided at her Retirement Home, so she was placed on an urgent waitlist for Long-Term Care. In November 2015, [her] friend and Power of Attorney … noticed that she was acting quite differently and had [her] taken to the hospital. [She] moved from the Emergency Department to the hospital's Complex Care Unit. While there, [she] … shouted at hospital staff and struck out at them. [She] became suspicious of her surroundings, telling [her friend] and staff that she thought she was being poisoned and at risk of being assaulted. She declined food and medication because of these beliefs. … [The older female, her friend], the BSO Clinical Leader, and the Community Care Access Centre worked to find a long-stay unit in a local Retirement Home that provided more care than did her previous home. [Her friend] reported that the hospital team provided the Retirement Home with a summary package containing [the older female's] medical, functional and behavioural care needs to enable a smooth transition." (17-1-07)

- "The goal was to transition the client into the same LTCH that his wife resides in. … To prepare for this transition, various care partners collaborated to ensure a smooth transition for the client. A client overview was provided to the BSO LTC Lead Team by the ASCK Day Program to provide a comprehensive overview of the client for the LTCH Internal BSO Champions/LTCH staff, the client's son-in-law and Home and Community Care BSO Care Coordinator were at the client's residence to provide support on day of admission, Mobile

Crisis Support Services were on standby to access support for the client if needed and a BSO LTC Lead Team PSW was awaiting client arrival at facility on day of admission." (18-1-01)

3.2.6 BSO Initiatives

Rather than consisting of a single clinical intervention, our historical review showed that BSO evolved as a framework for a mix of existing and new local initiatives to improve care for persons with responsive behaviours.

The qualitative stories confirm that this remains an accurate description. They document an array of individual-level initiatives aimed at addressing directly the person's needs and responsive behaviours. They also document a range of initiatives aimed at addressing needs indirectly by building organization and system capacity.

As such, the stories do not lead to a single best practice or "magic bullet." Instead they reveal how providers, often working collaboratively, grapple with complexity to find approaches that work for individuals, care partners, formal providers and the health care system. Approaches that work for one individual with particular needs and behaviours in a particular local context many not work for others and vice versa.

Nonetheless, the stories show that successful initiatives can be straightforward, low-tech, and low-cost. Persistence and a willingness to develop person-centred approaches seem to be key.

Successful *individual-level initiatives* (often employed in combination) include:

- Activity box/apron (e.g., interesting objects to sort, rummage through or collect)
- Activation strategies and techniques (e.g., planning activities which engage individuals meaningfully and encourage socialization and fitness)
- Aquarium or aviary (to provide visual stimulation)
- Behaviour reinforcement (e.g., positive responses to desirable behaviours)
- Changed location of care (e.g., from the bed to a chair or washroom)
- Communication in mother tongue (e.g., laminated cards with important phrases/ instructions in large print with English on one side and mother-tongue on the other)
- Consistent care approach (e.g., establishing individualized and familiar routines)
- Conversation, rapport building and kinship (e.g., staff taking time to understand the person and provide human contact; volunteers to provide extended companionship)
- Creating a calm environment (e.g., by spreading out meal times)
- Disrobing interventions (e.g., one-piece clothing, layering clothing, and using clothing with ties/buttons/zippers to keep clients' hands busy)
- Doll therapy (e.g., providing dolls to clients to "babysit")
- Family support and education (e.g., linking care partners to Alzheimer Society services)
- Gentle persuasion (e.g., "stop and go" technique)

- Hobbies (e.g., maintaining/rekindling past interests such as knitting, crochet, or flower arranging)
- Humour (e.g., jokes, seeing the funny side of everyday life)
- Massage (e.g., hand or body)
- Meaningful tasks with a purpose (e.g., a replica chart for a former nurse; mail sorting to "earn" fake money to "pay" for room and board; office work such as sorting, envelope stuffing; "assisting" the maintenance staff)
- Medications management (e.g., surveillance of polypharmacy, multiple prescriptions from different providers)
- Memory boxes/ reminiscence bins (e.g., photos, letters and familiar objects)
- Monitoring, managing and addressing behaviours that are biologically-rooted (e.g., pain, hunger, thirst, a full bladder, poor vision/hearing)
- Music (e.g., providing preloaded iPods to encourage individuals to listen to favorite music on low-cost, low-tech players while also dampening environmental noise)
- Observation (e.g., observing an individual's routines and factors triggering behaviours)
- Pet therapy (e.g., allowing "pet visitors" accompanied by trained volunteers)
- Physical activity (e.g., providing a ball to encourage movement)
- "Pocket talker" (e.g., providing a device to assist hearing and conversation)
- Redirection (e.g., gently guiding an individual away from something that irritates or upsets them)
- Signage (e.g., arrows pointing in direction where a client need to go; door markers to recognize own room)

Successful *organization-level* interventions include:

- BSO staff education and training
- BSO team support for individual assessment, care planning and monitoring
- Communication with all care team members
- Cultural translation/cultural sensitivity cards/training for staff
- Environmental modifications (e.g., lower lighting, quieter dining rooms, using vibrant colours in common areas)
- Flexible scheduling (e.g., letting clients get up and/or eat when they want)
- Ideas boards for staff
- Montessori training (e.g. how to create an environment filled with cues and memory supports that enable individuals to care for themselves and others)
- Peer counselling, coaching and mentoring
- Personal biography forms (i.e., personhood tools)
- Recognition of personal space (e.g., knocking, requesting entry to rooms)
- Resident Tip Sheets (e.g., 3 things to remember when entering a specific persons' room)
- Shift schedules to allow client care by a consistent PSW

- Staff "huddles"
- Readable staff name tags.

Successful *system-level* interventions include:

- Regional best practices sharing
- Regional networking (e.g., BSO personnel and collaborators including LTCHs, outreach teams, mobile teams, specialized geriatric teams)
- Regional training sessions (e.g., Gentle Persuasion Approach, Montessori Methods for Dementia).

Even while separating out interventions in this way, the qualitative stories emphasize that initiatives usually occur in combination.

At the individual-level, for example, initiatives such as gentle persuasion may be combined with meaningful tasks, music, physical movement and hobbies, serially, in an attempt to find the most effective approach, or concurrently to address different aspects of needs and behaviours. Similarly, non-medical interventions may be accompanied by episodic medical care (e.g., to address an infection) or ongoing treatment (e.g., pain management). Diversity issues may also come into play as individuals from different cultural, language, sexual orientation and faith communities respond to interventions which take such differences into account.

In addition, individual-level initiatives will often be accompanied by, lead to, or result from, organization and/or system-level education, knowledge mobilization and training aimed at improving practice and/or building capacity.

Stories focusing on *individual-level* initiatives include:

- "They identified triggers to her behaviours including noise and boredom. They also noted that [she] did not respond well when she felt that others 'told' her what to do. The BSO LTC Mobile team collaborated with [her] and her family to develop strategies to manage the responsive behaviours. [She] was moved into a private room, and during busy times of the day, the door to her room was closed. [She] was given a choice in what time her morning care would be provided. [She] was trialled with several Montessori activities which provided purpose and minimized boredom. Cultural translation cards were given to the hospital staff to foster more effective communication." (16-1-06)

- "The team met with this individual multiple times. They completed a thorough social history, and built a relationship with this individual. They discovered that the client loved to watch movies in a La-Z-boy chair, play cards, enjoyed golf and animals, liked to work with his hands, and enjoyed Tim Hortons. … the BSO-embedded team created a "tip sheet" for staff to review to better understand this resident. The home set up a La-Z-boy and television ahead of time to help this resident feel at home. On the day of the transition, the

BRT and client met at Henley Place, and the staff, client, family, and BRT had coffee and Timbits together while touring the facility." (16-4-04)

- "This client has always enjoyed fixing things and has been found numerous times by various LTCH staff attempting to fix various objects around the LTCH. While GMHOT worked closely with the physician to correct the client's sleep pattern with medication, the BSO LTCH Lead team provided various holistic recommendations … includ[ing] the creation of an activity box, which was to include nuts and bolts, sanding blocks, and some small pieces of wood. .. created a mail program for the client, where a staff member would accompany the client on a walk to the LTCH's Administration office to pick up his 'daily mail'. The client's caregivers [care partners] even provided the LTCH with various notes, letters, and flyers to provide to the client when he comes to collect his mail. … These interventions included creating 'fake' money for the client, as paying for food and services is important to the client." (17-2-02)

- "The strategies that were collaboratively developed and used included: Developing a job that fit with [a female resident's] characteristics and interests. [She] created and delivered cards to staff and co-residents to celebrate their milestones. Soon, a calendar was made to track the occasions for which [she] would make a card. … Making the cards gave her a sense of purpose and meaning. … Providing an iPod loaded with some of [her] favourite music. [She] received her iPod several times throughout the day, and enjoyed listening to the music. …Creating two baskets filled with [her] favourite items, including jewelry, treats and makeup." (18-1-07)

- "Staff introduced activities which were relevant to client during the initial rapport building phase. Instead of expecting client to remain in program activities, staff allowed for client to leave the activity and walk about, staff showed client where he could safely walk about as an independent activity. … Client often feels the need to eat so staff would have a plate with culturally specific food which is supplied by family. Small portions of food would be put on a plate to avoid client eating everything all at once or sharing all his food with other clients. … Client has a strong need to feel valued and relevant. This need is supported by providing purposeful activities which replicate household tasks he does at home such as folding laundry and cleaning dishes. … Since religion still has a significant impact on client's emotional well-being, an i-pad/computer are available for client if he wants to listen to Quaran readings in either in Punjab or Urdu. A quiet area has also been made available for client to pray. The area is marked with a visual aid; a symbol of a mosque with a man praying, a mat is also provided." (18-4-11)

Stories documenting *organization or system-level* initiatives include:

- "After attending a Knowledge Exchange opportunity in which part of the focus was on education about aromatherapy, LTC home staff incorporated a five minute hand massage into the morning routines of clients on the BSO caseload. The staff gave the massage each morning to the same group of residents … Staff observed that they have not had any episodes of responsive behaviours from this group of residents since the addition of the 5 minute massage to the morning routines. The group will be completing a PDSA to better understand their findings." (16-1-08)

- "Small increments of change have continued to occur including the goal for all residents to be safe from falls. Doll therapy has been the most significant influence on the resident population. Through the work of [the] activation team … she has engaged residents and staff in new and meaningful ways to make positive changes. Involving of the resident council and management team has assisted in shifting the culture of the home. Additional strategies to support identification and connecting with the residents have come with the recent introduction of the "All about ME" information cards created for all the resident home areas. Brightly coloured staff name tags with bold black font on a yellow background additionally have aided in identification of staff for the residents and family visitors. A designated creative arts corner on the 3rd floor and a nursery for doll therapy is a further adaptation at Westside NH." (16-3-09)

- "Improving the capacity and knowledge of all members or our BSO teams is an important component in providing high quality care to those we support. We have been able to provide an education blitz in our long term care sector, focusing on core competencies. In [this] LHIN, we are also taking strides to follow up not only core education, but any training we provide with support in embedding that education. We are working with our long term care homes on strategies to put knowledge to practice that are effective and reasonable for the home and staff to accomplish. Each long term care home may face very different challenges and successes when it comes to utilizing the training and knowledge of their internal teams and BSO is working to individualize knowledge to practice strategies for each home." (17-3-02)

- "The education offered to the Acute Medicine Units was created by the BSO team in collaboration with Education and Development Clinicians. The simulation scenarios and content were created to directly target the behaviours and challenges most commonly encountered by teams on the units. … After the education, participants reported increases in their self-reported feelings of comfort, knowledge, and safety when working with [people living] with cognitive impairment and responsive behaviours." (18-1-08)

- "As the BSO Lead Team for [regional] LTCH's, we have the privilege of connecting with Internal Champions on a frequent basis. Developing successful relationships with our champions has been a very rewarding experience, as each team is unique, yet shares a passion in supporting residents with responsive behaviours. … As an external team, we are able to provide Internal Champions with support and guidance to perform their roles. This may be in the form of mentorship, sharing successful experiences and processes from one Internal Champion team to another, ongoing education, and most importantly, validation. " (18-2-01)

- "… [LHIN] BSO has developed a Knowledge to Practice (K2P) PSW Working Group with the PSWs from the four BSO Lead Teams. The group was developed to review Dr. David Ryan's Knowledge to Practice Framework, and provide information about gaps and potential strategies to help PSW's in long-term care homes apply what they have learned into their practice. The group discovered that many PSW's in the long-term care homes are compassion fatigued. The PSW's in the K2P Working Group have developed a knowledge base about compassion fatigue and have begun to develop education about this topic to support staff working in long-term care homes." (18-3-01)

3.2.7 Impact

As noted in our historical review, since 2015 the single BSO legacy outcome measure focuses on change in behavioural symptoms among LTCH residents.

The qualitative stories suggest, however, that positive outcomes accrue more widely. Many noteworthy successes are reported in community and hospital settings as well as in LTCHs. Moreover, in addition to the person with responsive behaviours, a range of positive outcomes are reported for care partners, formal care providers and the health care system as a whole.

As we have seen, interventions may have a preventative function; their goal is to avert the escalation of behaviours or manage them in place. In addition to improving outcomes for individuals, stories suggest that such "upstream" interventions can also impact positively at a system level by moderating demand for hospital admissions, avoiding crisis placement to a LTCH, smoothing transitions, and preparing staff at receiving organizations with intelligence and care strategies to better manage workloads and increase impact.

BSO initiatives may also have a restorative function, stabilizing and managing behaviours so that individuals can return home after a hospital visit, or access a more appropriate care setting such as a retirement residence or LTCH, including those which had previously refused to accept them, or discharged them because of unmanageable behaviours. In addition to benefitting individuals, hospitals can benefit by being able to discharge patients to a more appropriate care setting in a timely manner thus impacting positively on ALC rates. LTCHs can benefit by having a developed care plan in hand at the point of admission. By being better prepared, staff in

different care settings may be less fearful for their own safety and security, and more willing to go that extra step to develop creative person-centred solutions that work.

Whether preventative or restorative, the qualitative stories emphasize that benefits to care partners should not be overlooked. As a recent expert panel in Ontario concluded, in home and community, the "unit of care" includes both the cared-for individual and care partners without whom the health care system could not sustain current levels of care.[21] Particularly when individuals with responsive behaviours cannot make decisions for themselves, care partners become their voice and an essential source of insight and direct support for formal providers in the community, hospitals and LTCHs. Caregiver education, training and counselling as well as instrumental supports such as respite, can make care partners more resilient and willing to care in turn moderating demand on a stretched health care system.

We categorized positive outcomes into three broad categories at individual, organization and system levels, noting that these frequently overlap.

At the *individual-level*, stories highlight the following outcomes:

- Caregiver no longer fearful/more confident
- Caregiver relief/less anxiety
- Caregiver willing to accept individual back into the home
- Caregiver willing to continue to provide care
- Client able to remain/return home
- Client less agitated/restless
- Client more willing to accept care
- Decreased risk of injury for other clients and residents
- Family experiences less stress and worry
- Family willing to reunite
- Greater willingness of client to engage/socialize with others
- Improved sense of worth
- Increased wellbeing and quality of life
- Reduced verbal and physical expressions of risk

Positive outcomes reported for *organizations* include:

- Enhanced staff feelings of comfort, knowledge, and safety when working with people experiencing cognitive impairment and responsive behaviours
- Fewer staff sick days
- Greater staff satisfaction

[21] Ontario. Report of the Expert Group on Home and Community Care. Gail Donner, Chair. 2015. Accessed on-line, July 2018, at http://health.gov.on.ca/en/public/programs/lhin/docs/hcc_report.pdf .

- Greater staff willingness to try new approaches
- Improved teamwork/collaboration
- Reduced resident behaviours
- Reduced resident falls
- Reduced staff anxiety and fear
- Reduced staff turnover
- Staff more confident in their ability to manage complex situations
- Time/effort saved for staff

Positive outcomes for the *health care system* include:

- Avoided hospital admissions
- Avoided LTCH crisis placements
- Best practices sharing and capacity building
- Clients able to remain at home or in another community setting (e.g., retirement home) moderating pressures on LTCHs
- Greater collaboration and teamwork
- Reduced ER visits
- Reduced hospital ALC days
- Reduced 911 emergency calls and police involvement
- Return to original care setting (e.g., home, retirement residence, LTCH)
- Smoother transitions between care settings.

The following excerpts illustrate *individual-level* outcomes (recalling that positive outcomes often occur at multiple levels simultaneously):

- "Through the collaborative efforts of all involved, a change in Maria's disposition was noted. Maria appeared brighter and happier, and tracking of her behaviours showed her LTC home that the strategies were helpful. After reviewing this information, Maria's LTC home agreed to accept her back and to use the strategies that successfully addressed her responsive behaviours while in hospital." (16-1-05)

- "Harry is more relaxed, has reduced episodes of responsive behaviours noted over the last few weeks and is being managed effectively on his other dementia medications. Harry continues to progress with positive changes and monitoring continues to reinforce his improved personality. Staff are relieved and are able to engage in a more meaningful way as they know more about the root issues regarding Harry's pain and behaviour." (17-1-08)

- "Hospital staff reported that, after implementation of the behavioural care plan, Martin appeared more calm and happy, and was able to sleep better at night time. Martin's spouse and family felt less stress around his behaviours once the behavioural care plan was put in

place and his responsive behaviours became more manageable. Being transitioned to his home hospital meant that Martin's wife could visit him more easily, and his family physician could follow him, thereby promoting continuity of care. Having Martin staying on a typical hospital unit (instead of a mental health unit) helped to demonstrate his readiness to move into Long-Term Care, facilitating a more timely transition out of hospital, and into Long-Term Care." (17-4-07)

- "Deborah is able to take part in meaningful activities throughout her day, and has a strengthened sense of value and purpose in her day-to-day life. Deborah's family has also been positively impacted by the changes in her care plan, as they know that their family member is engaged in her preferred activities and cooperating with staff and co-residents. By collaborating with team members with varied expertise, staff from both BSO and the LTC home were able to gain new tools and resources that will enable them to support residents in the future who have needs similar to Deborah's." (18-1-07)

- "The impact of this successful transition was significant for the spouse and other informal caregivers [care partners] who were providing support in the community. Spouse reports an "incredible feeling of relief" knowing that he is safe and cannot exit home to wander community. Spouse now attends home for regular visits and shows improvement in caregiver stress, enjoying her visits. Significant for the new internal BSRT was the experience of supporting their 1st successful transition from community into the home for a person whose applications to LTCHs had been previously declined." (18-1-13)

Excerpts illustrating *organization-level* outcomes include:

- "… good relationships were built with LTC staff. LTC staff were also happy to carry out strategies because they felt empowered, and felt that that they had the support from BSOT and other outreach teams. LTC staff felt more motivated to continue implementing the aforementioned strategies because BSOT ensured to heavily collaborate with LTC staff and make them aware that the strategies were their ideas. … LTC staff were also more receptive in trying other strategies because they felt that they had the support of BSOT. As a result, Ms. A's behaviours decreased significantly in intensity and frequency, and she was able to be discharged from BSOT." (16-2-07)

- "With increased participation in meaningful activities, this resident will have the opportunity to further thrive in his LTCH environment with a sense of purpose and fulfillment. This, in turn, may alter his impact and social connection with other residents. Bringing activation staff and programming to the forefront of the responsive behaviour supports for this individual will embrace recreation and activation professionals as a

valuable and recognized part of the integrated support team. " (17-4-01)

- "A pre- and post- survey was completed with staff on the Acute Medicine units who participated in the education. After the education, participants reported increases in their self-reported feelings of comfort, knowledge, and safety when working with [people living] with cognitive impairment and responsive behaviours. …The education offered was well-timed, as it enabled hospital staff to challenge their beliefs and values related to responsive behaviours, and apply new learning to help [her] settle and transition out of the hospital." (18-1-08)

- "Staff feel more confident in their abilities to overcome complex situations. …They are more open and willing to try new ideas and ways of looking at situations. Co-residents feel supported and most have grown accustom to Mr D's behaviour and acknowledge his actions as not deliberate but the result of disease. … Resident has "settled" into his home unit. Although he continues to wander, he no longer voices negative thoughts. Resident's spouse feels supported and confident in the staff's ability to care for her husband." (18-3-03)

- "Behaviours across the home have been reduced by about 50%. Residents that wanted to now be involved were now busy doing the things they loved to do. Falls have been reduced by 25%. At the onset of the quality improvement behaviours were at 97 episodes in the month of November 20 17. In March 2018 they were reduced to 66 episodes." (18-4-10)

Excerpts showing *system-level* outcomes include:

- "Averted ED and tertiary care transfers … Staff were more confident providing care." (16-4-16)

- "… there has been no hospital admission or ER visit, no police contact and no significant anger/aggressive outbursts …The client's wife is slowly building capacity within herself and her family to respond in more creative ways and communicate differently with the [client] to help maximize his strengths and not highlight his deficits." (17-1-04)

- "Client continuing with activities that are important to him at the community centre … Staff are no longer calling the police and better able to manage situations that arise. … Spouse who has her own health concerns has expressed a decrease in her stress level and is better able to cope with client's behaviour in the home." (17-3-05)

- "Increased knowledge transfer beyond the circle of care-health care system … Informed community partners with a goal of enhancing opportunities towards a senior friendly

community … Enhanced partnership with the Adult Day Program … Emergency Department visits in response to the community calls to the police have ceased … Town officials/community centre expressed their awareness of addressing the needs of individuals with dementia presently and in the future has been positively impacted … Awareness of dementia has increased in this small rural community." (17-3-08)

- "The transition of [residents] to and from the … LTCHs and the … Hospital, Seniors Specialized Mental Health Program exemplifies an integrated multidiscipline and intersectoral collaboration. By recognizing the value of collaboration, all care providers "speak the same language" … " (18-2-06)

3.2.8 Key Lessons Learned

In addition to documenting successes to date, the qualitative stories provide "lessons learned" to inform future initiatives, although not in a standardized "cookbook" format. Rather, these lessons point to design fundamentals that can be applied to support people with widely varying needs and behaviours in very diverse contexts.

We identified five key lessons learned from the qualitative stories, all closely aligned with the BSO framework, and with work previously conducted by the BSO Provincial Coordinating Office (PCO). [22] These lessons highlight:

- Person-centred care
- Family and informal caregiver engagement
- Interdisciplinary and intersectoral collaboration
- Managed transitions
- Knowledge mobilization and capacity building.

Person-centred care

Consistent with a growing emphasis on "patient-centred" care nationally and internationally,[23] and with the BSO framework itself which puts at its centre older Ontarians with responsive behaviours and their care partners,[24] a first key lesson is aptly described in one story as "understand the person." In the case of "Mrs. D," a nursing home resident, this meant that the "team began to know her and better understand the person behind the behaviours" which included a traumatic past. This understanding was crucial to generating insight into how a

[22] Behavioural Supports Ontario, Provincial Coordinating Office. Annual Report 2015-16. Accessed on-line, August 2018, at http://brainxchange.ca/Public/Files/BSO2/BSO-PCO-Annual-Report-2015-16.aspx
[23] See, for example, Kuluski K, Peckham A, Williams AP, Upshur REG. What gets in the way of person-centred care for people with multimorbidity. Lessons from Ontario, Canada. Healthcare Quarterly, 19(2) July 2016. Accessed on-line, August 2018, at https://www.longwoods.com/content/24694.
[24] Behavioural Supports Ontario. Provincial Framework of Care. Accessed on-line, August 2018, at http://www.behavioursupportsontario.ca/25/Provincial_Framework_of_Care/

"seemingly impossible situation" could be turned into a "new opportunity" for the resident and staff learning. (17-2-10)

This lesson appears repeatedly throughout the stories as an essential ingredient of best practice. As we have seen, BSO clients typically have complex needs and behaviours. In addition to cognitive impairments, many experience combinations of health and social needs, sometimes compounded by inappropriate or ineffective health system responses. Moreover, BSO clients continue to hold personal preferences and aspirations which condition their responses, to initiatives meant to improve their care.

What this means, the stories suggest, is that "knowing the person" through ongoing conversation, observation, assessment, and teamwork, is not a frill; it is a crucial prerequisite for the design and implementation of effective approaches that work for the person, and make the best use of resources available at the local level.

Stories highlighting *person-centred care* include the following:

- "Partnerships between those who know the residents best, BSO, Specialized Geriatrics, and LTCH staff can result in the creation of individualized care plans, while building capacity in staff so that they can meet the diverse behavioural needs within their home. Individualized, developmentally-appropriate interventions may contribute to positive outcomes for clients, families, and staff alike." (17-2-09)

- "Each individual is different. Every person will have a different staff member they connect to, a different intervention that will work for them. The residents, when given the chance, appropriate supports and ability to achieve something, will often succeed." (17-4-30)

- "… knowing the client's history, validating his emotions, meeting him where he is at and collaborating with care partners has led to our reassurance that he is in a safe environment with his wife." (18-1-1)

- "It is important to know the history to be able to understand behaviour and emotion. …Try to see the resident's perspective and not your own. … Let the resident have control over things that he can control." (18-1-17)

- The story of an older male transferred to hospital then to LTC and then back home in the community "… represents the importance of looking at clients in a holistic manner. Specifically, the P.I.E.C.E.S. model prompts care providers to consider client's capabilities and strengths. [He] was never told that his goals were too lofty or unrealistic. Rather, his team embraced his determination, and worked with [him] to maximize his function. This

strengths-based approach holds value for all clients served by BSO - regardless of their functional level." (18-2-07)

Family and informal caregiver engagement

A second lesson concerns the importance of engaging family and other care partners, where present, not just as a courtesy, but as full partners in needs assessment, care planning and delivery. Even if care partners are not officially members of care teams, their willingness and capacity to provide ongoing support are essential for successful initiatives.

As observed earlier, the caregiver role is particularly evident in the community where family, friends and neighbours provide the bulk of the 24/7 care needed to maintain older persons with responsive behaviours as independently as possible, for as long as possible.

Care partners are also pivotal to returning a cared-for person home following a hospital visit, since without care partner buy-in and support, a successful return is unlikely. Moreover, the care partner role continues in hospitals and in LTCHs where their personal insights, emotional support and direct care appear repeatedly as vital resources. As well, care partners can help bridge cultural, language and religious divides in an increasingly diverse population.

The quotes below speak to the importance of engaging actively with, and supporting, *care partners*:

- "Family and informal caregivers [care partners] are crucial to understand the needs of the person; Open communication; share as much information as possible among the team; Use a person- centred/ individualized approach; must be compassionate, respectful, consider culture and language in care." (16-1-11)

- "Rapport building with family members and client was very instrumental in overall effectiveness of providing education and support. … Client's caregivers (spouse and family) [care partners] were well supported despite the changes to caregiving roles. … Caregiver burden/grief can act as a significant barrier to accepting community supports." (16-4-07)

- "By working with the family over time, listening to their questions, communicating clearly, and incorporating their goals into the treatment plan, the COT worker developed a strong rapport with the family. The COT worker completed the following interventions to support [an older woman] and her family … The COT worker also provided [her] children and spouse with education regarding Montessori approaches to dementia care and engagement in meaningful activities. In order to ensure clear communication, she modelled the techniques, and had the family attempt them in the moment." (17-2-07)

- "Care planning with team and family created successful interventions … Smooth transition for the [client] from home to LTCH with effective communication between all parties …

Family support is invaluable when putting interventions into place." (17-3-12)

- "Communication between all members involved with [client's] care is so important to develop an effective care plan. The approach of caregivers [care partners] can make a huge difference for client's living with dementia and some approaches often lead to responsive behaviours being triggered." (18-1-15)

Interdisciplinary and intersectoral collaboration

A third key lesson learned, also well documented in the qualitative stories, concerns the importance of joint working and collaboration between care providers from different disciplines and perspectives, within and across organizations and sectors.

Although conventional health care systems focus on episodic curative care for well-defined illnesses or medical conditions, persons with responsive behaviours typically present with "multi-morbidities," often complex combinations of chronic health *and* social needs which cannot be cured, but must be managed on an ongoing basis over the long term. Moreover, BSO clients often transition between care settings in the community, hospitals and LTCHs, highlighting the need for communication, continuity and collaboration along the entire care pathway.

Given this complex reality, multi-layered teams seem essential for effective person-centred care. As the stories emphasize, this is not just a matter of doing "nice" things for people; it is also a matter of making the most effective use of available resources.

The following quotes highlight the importance of *broad-based collaborations* within and beyond health care:

- "A care conference was held 03/16/2016 at the LTCH. The outcome of the meeting included a commitment that proper medication administration would be addressed with staff; PRC would stay connected with the LTCH and a prior staff member of hospital who had supported this individual and expressed a willingness to mentor staff and exchange knowledge at the LTCH; the family would provide a summary of tips/techniques for managing Mr. Z's behaviors; BSO Lead Team would continue to work with Internal Champions to mentor staff about approach; education and capacity building would be arranged with BSO Regional Education Coordinator." (16-4-03)

- "The BSO Connect Representative directly called the Senior's Support Police Officer and the Behavioural Supports Ontario Community Outreach Team and explained the situation so Dina wouldn't have to repeat her story. … The Senior's Support Police Officer collaborated with the Community Outreach Team to develop a plan for supporting [husband] and [wife]. … The BSO Connect Representative completed a referral to the Community Care Coordinator of CCAC and spoke to them advocating for the Community Care Coordinator to

make a prompt home visit … The BSO Connect Representative also prepared a My Health GPS package for [the wife] and mailed her information regarding long-term care homes and other supports. … The BSO Connect Representative utilized their geriatric training and expertise in services and supports to assist [the wife] in getting immediate help from the most appropriate service providers …" (16-4-09)

- "An interprofessional team approach (LTCH staff, physiotherapist, BSS Mobile Support Team, Geriatric Mental Health Outreach Team, NLOT NP, PRC, [name of team member]) offers a holistic approach for optimal care that will best support individuals with inter-related complex health needs and responsive behaviours." (17-3-11)

- "The BSS MST [mobile support team] communicated and modelled their care strategies to the BSS in-home team and primary PSW providing care. … The in-home BSS Team will monitor and ensure that the behavioural strategies are continued and that JJ remains calm. Trained BSS Teams within the LTCH working collaboratively with specialized teams from outside the LTCH can achieve wonderful results for the resident, family and staff!" (17-4-13)
- "The collaboration among the staff at the Neuropsychiatry Unit, LTCH, NLOT, BSO Lead Team, GMHOT & the BSO SN has focused supports to best meet the needs of the resident. … Clear communication and collaboration have been key elements among the teams working to bring about stabilization for this resident. It has not come without challenges but it has been a wonderful opportunity to learn about each other's perspective roles, gain a better understanding of how each organization functions, and most especially has created a *patient centred approach to care.*" (18-1-02)

Managed transitions

A related fourth key lesson learned concerns the importance of carefully planning and managing transitions for persons with responsive behaviours and their care partners.

While most individuals with responsive behaviours begin their journeys in the community, LTCHs are not necessarily the final end point. As the qualitative stories document, transitions to and from hospitals occur with some frequency. Community-dwelling persons may be admitted to a hospital following a behavioural episode or caregiver burnout and returned home following specialized care. Similarly, individuals residing in a LTCH may be sent to hospital when their behaviours are judged to be unmanageable, and they may subsequently return to the LTCH when behaviours subside.

As the stories show, transitions between care settings almost always pose challenges and risks for persons with responsive behaviours, as well as for care partners, formal care providers, other clients and residents, and the health care system. In fact, poorly managed transitions can themselves lead to an escalation of behaviours, requiring substantial, and potentially avoidable, investments of informal and formal resources.

The following quotes from the qualitative stories illuminate the importance of *well-planned and managed transitions*.

- "The BSO CL provided a 'warm hand-off', including a thorough update of Mr. A's situation to the BSO LTC Mobile Team to support Mr. A's transition into the LTC home. Two members of the team were present at Mr. A's LTC home on the day he arrived to ensure he and his family felt comfortable with the transition, and pass along the effective strategies to staff at the home. The daughter-in-law now reports that her father-in-law is settling in "fabulously" in his new home, and stated: "The [BSO Clinical Leader] was my lifesaver". … With collaborative transitions and support by the BSO teams, effective behavioural care plans can be shared with future providers of care to ensure smooth transitions, as in this case with transitioning from hospital to Long Term Care." (16-2-04)

- "The client has been impacted by the level of care provided by the LTCH, BSO, and hospital. Due to changing medical needs, the client has endured several changes in location which impacts the care she receives and her daily routine - Client is benefiting from the collaborative approach taken by hospital staff and Management, BSO CCAC Care Coordinator, BSO LTC Lead team, BSO System Navigator and Regional Coordinator Lessons learned:- The importance of working in collaboration with system partners to achieve positive outcomes for our clients." (16-4-02)

- "After arriving at the hospital, [Mr M] remained on the unit for two weeks with very little improvement in his responsive behaviours. After the individualized behavioural care plan was put into place and used by all staff, [Mr M] improved enough for the involuntary status to be removed. He was then transitioned from the mental health unit to his home hospital to await a bed in Long-Term Care. … Being transitioned to his home hospital meant that [Mr M's] wife could visit him more easily, and his family physician could follow him, thereby promoting continuity of care." (17-4-07)

- "Transitions remain a very vulnerable time for clients and communication is integral to a successful transition. MRT were the conduit to the successful transition for this resident. Collaboration of all partners is also an essential component to the success of the transition and ensuring quality of life for the clients and families." (17-4-16)

- "By reaching out to our resources prior to accepting resident's application we were equipped with a strong plan and skilled team for her transition into our home. It is important to ask for support before you are overwhelmed. By taking a chance on a resident who had been declined by other homes and being "vulnerable", our team was able to learn how strong we are." (18-2-18)

Knowledge mobilization and capacity building

A fifth key lesson learned addresses the importance of robust mechanisms for knowledge mobilization and capacity building, between providers and organizations, and across sectors and regions.

Although the stories show how successful interventions are almost always tailored to the needs of the individual, they also emphasize that there is much to learn from the experiences of others, and that providers in all settings are usually keen to know about new approaches to improve the lives of clients and make staff workloads more manageable and fulfilling.

One mechanism for doing this is staff meetings and training events within an organization. For example, stories show how learning about the P.I.E.C.E.S. Framework and related tools can improve staff confidence and ability to understand needs and behaviours. Peer counseling and mentoring can strengthen working relationships among staff. Learning from experts about creative interventions such as music or doll therapy can provide new ideas and energy for effective care.

Inter-organization learning often occurs as a result of collaboration and joint working. Such learning can happen episodically, as diverse teams work to address the needs of a particular client, or it can happen on a planned basis, often encouraged and supported by BSO experts.

System-level learning is highlighted in stories about regional best practices forums, or special presentations and education offered on-line, in which best practices or promising approaches are widely shared.

The key take-away is that knowledge mobilization at all levels can and does play an important role in building capacity. Knowledge mobilization and sharing also appear to be essential ingredients for spreading and scaling success, not just through the interchange of information, but through the stronger working relationships and "buy-in" that occur as a result.

The excerpts below speak to the importance of knowledge mobilization and capacity building.

- "Engaging in ongoing opportunities to not only learn formally, but informally from the expertise that exists among our teams creates an increase in capacity and greater collaboration, integration and support. This all results in a stronger support system for those in our care." (17-3-02)

- "There were a total of 4,457 registrants across 331 BSO-related training events including GPA, GPA Coach, PIECES, U-First, Validation Communication, Montessori Methods, Mental Health First Aid for Seniors, ASIST, Applied Behaviour Management; also funded PRCs and PECs to attend advanced train-the-trainer events to increase their capacity. .. [As a result] there is a much deeper understanding and common recognition of the fundamental belief that "all behaviour has meaning" along with a renewed excitement and momentum to

implement the new skills and learnings. The full impact of this increased capacity to support people with responsive behaviours in long term care and in the community is yet to be realized." (17-4-12)

- "Through the BSO education 2016/2017 education funding the home has been enabled to increase education and training sessions for all staff. As a result staff have an increased capacity in assessing and planning interventions for those with responsive behaviours. This is evidenced with this resident's success story through the use of the P.I.E.C.E.S. framework, working together as a team and using a multidisciplinary approach. This is one of the most successful cases in our Long-Term Care home as resident improved both physically and emotionally." (17-4-14)

- "Having tools and resources are essential when spreading and sustaining any initiative. By continuing to provide education and training to our staff it has allowed our BSO program to grow and spread to all staff and family. Getting everyone involved is also very key as their input can provide valuable information and it empowers them and others when they see the difference they can make. We were able to train more staff and continue to spread and sustain our program. We have seen increased buy-in from staff from all disciplines and this is from getting everyone involved." (17-4-15)

- "Education remains a priority for not only internal and external BSO teams, but LTC staff as a whole. The more tools we continue to build, the more improvements we can make to the care we provide our residents...as a team!" (18-4-02)

4.0 Summary and Recommendations

4.1. Summary

Ontario, like other jurisdictions nationally and internationally, is now facing an aging population with an associated rise in the numbers of older persons living with dementia as well as complex neuro-cognitive and mental health conditions.

Responsive behaviours are also on the rise. Behaviours such as physical expression of risk in LTCHs have been widely reported in the media because of their visibility and serious impact on others. Yet, less visible behaviours such as anxiety, depression, fear, withdrawal and unwillingness to accept care, can also have a profound impact on the wellbeing, independence and quality of life of the individuals experiencing them, and on care partners, formal care providers and the health care system.

Building on the foundations of earlier provincial dementia policy development, Behavioural Supports Ontario (BSO) emerged progressively over almost a decade as a principle-based

framework for existing and new local initiatives to address responsive behaviours wherever they occur across the care continuum.

As we noted in our earlier report, previous evaluations have documented a range of benefits arising from BSO, albeit mostly in LTCHs. These include more timely intake and access to care, improved quality of care, teams better prepared to work together, enhanced capacity building, and lower rates of hospitalization in early adopter LHINs.

The 253 qualitative stories submitted by Ontario's LHINs during the three year period 2015/16 to 2017/18 add new depth and detail to this evidence base. These stories reveal both the complexity of needs and behaviours now being seen in community, hospital and LTCH settings across the province and the ability of collaborations spanning disciplinary and organizational boundaries to create innovative person-centred solutions at the local level that improve the lives of people and make the most effective use of available resources.

The main findings of our in-depth review of the qualitative stories can be summarized as follows:

- Responsive behaviours are not a single, uniform phenomenon; they have many different, complex manifestations. The stories show that behaviours such as verbal and physical expression of risk often present in combination with others such as pacing, depression, anxiety, withdrawal, and unwillingness to accept care making them inherently challenging to diagnose and manage.

- Underlying needs are similarly multifaceted and diverse. In addition to dementia, mental health, addictions and cognitive challenges, BSO clients often experience multiple chronic health issues (e.g., arthritis, diabetes, heart conditions) complicated by social deficits (e.g., poverty, family breakdown, social isolation) and inappropriate or ineffective health system responses (e.g., prescribing errors, inadequate pain management, long hospital stays contributing to decline).

- First contact with BSO takes place in settings across the care continuum. While many such contacts occur in LTCHs, they also occur in the community (e.g., family home, adult day program, retirement residence) and in hospitals (acute care, continuing care, psychiatric facilities). Indeed, the stories suggest that earlier, "upstream" interventions can sustain persons with responsive behaviours and care partners at less intensive levels of care longer, thus moderating pressures on LTCH beds, or at the very least, laying the groundwork for smoother transitions to LTCHs when they are required.

- Given the complexity of the challenges now being faced, it is not surprising that multifaceted teams and collaborations that can access specialized skills and resources

within and beyond health care, are hallmarks of BSO successes. In addition to engaging health care providers in settings across the care health continuum, stories point to the vital contributions of partners such as the Alzheimer Society, community agencies, and police services. They also underscore the crucial role of care partners who, in addition to providing essential day-to-day care and support to persons with responsive behaviours in the community, often continue to provide invaluable insight and support to cared-for persons and staff while in hospitals and LTCHs.

- Transitions between care settings are critical points in care journeys which, if poorly managed, can themselves contribute to escalating behaviours. Transitions typically involve movement from a lower intensity care setting (e.g., the family home) to a higher intensity setting (e.g., a hospital or LTCH). However, they may also involve a return back to an original setting (e.g., the family home, retirement residence or a LTCH) following an acute episode. Proactive assessment and planning by inter-disciplinary, inter-organizational organizational teams can smooth transitions, ensure continuity of care, and better prepare receiving organizations (e.g., LTCHs) to respond.

- Rather than identifying a single "magic bullet" or "best practice," the qualitative stories show that BSO successes often incorporate a mix of approaches at individual, organization and system levels, including many that are low tech and low cost. Music, conversation, staff huddles, and regional training sessions, all offer potential to improve care for individuals and build organization and system capacity. Here, the concept of "person-centred" care seems crucial, since approaches that work for particular individuals in particular contexts, may not work for others, or in different contexts. "Understanding the person," including individual preferences, aspirations, and cultural, language and religious experiences, appears to be key to providing care that can improve the lives of individuals, reduce risks to others, make staff workloads more manageable, and improve staff confidence and satisfaction.

- Benefits are widely distributed. In addition to positive outcomes such as enhanced wellbeing and quality of life for individuals with responsive behaviours and care partners, BSO initiatives are seen to generate benefits organization and system levels. These include providers who are better equipped to manage responsive behaviours without compromising the care and safety of others, and the health care system which may face fewer avoidable 911 calls, ER visits, lengthy hospital stays, and crisis LTCH admissions.

- "Lessons learned" are closely aligned with, and reinforce, the provincial BSO framework. They speak to the importance of person-centred care; family and informal caregiver engagement; managing transitions; interdisciplinary and intersectoral collaboration; and

knowledge mobilization and capacity building. These lessons directly respond to the increasing volume and complexity of needs and behaviours by accessing diverse perspectives, skills and resources from health care and beyond, and the importance of continuously building knowledge and capacity to meet new population needs into the future.

4.2 Recommendations

The qualitative stories bring home the fact that responsive behaviours present new and often daunting challenges for people, providers and the health care system in Ontario.

Nevertheless, these stories are essentially optimistic. Not only do they show that much innovative work is already being done under the BSO umbrella to create collaborative, interdisciplinary, intersectoral care for persons with responsive behaviors, but that there is also considerable potential for future gain.

Our in-depth review of the stories suggests that, building on successes to date, BSO is well positioned to continue to play a key role in achieving that potential across the province.

In the spirit of the BSO framework's three pillars, we offer three recommendations distilled from the qualitative stories to build local capacity and promote the spread and scale of successful initiatives across the province.

Recommendation 1. Reaffirm person-centred care as a core value

Our first recommendation highlights and reinforces what is already at the heart of the BSO framework: persons with responsive behaviours and their care partners.

A key message from the stories is that person-centred care is not a frill. Particularly when needs and behaviours are multifaceted and chronic, "knowing the person" and creating individualized care plans that make the most effective use of available resources, is not only good for people, the health care "top line," but good as well for the health care "bottom line," system sustainability.

The three pillars are essentially means of achieving the goal of person-centred care. They constitute a "toolbox" for care that improves the lives of persons with responsive behaviours while also generating a range of tangible benefits for providers and the health care system. As the qualitative stories demonstrate, it is this goal of person-centred care that drives the development of the innovative approaches documented in the qualitative stories. As the stories show, not all approaches work every time; failures occur along the way. But the idea of elevating the person motivates many providers to persist and to take risks by trying something new.

The stories also clarify that person-centred care almost always involves care partners when they are present. As a recent expert panel in Ontario concluded, in home and community where care partners provide the bulk of everyday care required to maintain the wellbeing and independence of older persons, the "unit of care" almost always includes both the cared-for person and the caregiver.[25] The BSO qualitative stories go further to show that for persons with responsive behaviours this broader unit of care often continues in hospitals and LTCHs where care partners continue to play a vital if largely undocumented role. When persons with responsive behaviours cannot speak for themselves, care partners become their voice.

Moreover, by giving greater recognition to the role and contributions of care partners, there is also greater appreciation of the fact that care pathways are neither unidirectional nor inevitable. Although almost all pathways begin in the community, they do not necessarily end in long-term care beds. The stories show that even for individuals with high, complex needs and responsive behaviours, informal caregiver contributions can alter the care path by preventing or delaying transitions to hospitals and LTCHs. Caregiver buy-in is also essential for returning people home after an acute care episode. In this sense the qualitative stories may actually underrepresent caregiver contributions and successes, since these stories only report cases which become "visible" to the health care system usually because they are problematic. Many other cases likely remain "invisible" because care partners persist without calling for help, even at high cost to themselves.[26]

This, in turn, highlights the value of proactive initiatives aimed at identifying and supporting persons with responsive behaviours and their care partners as early as possible along the care pathway before problems escalate to the point that 911 calls, long hospital stays, or crisis placements to LTCHs become the only options. In fact, as the stories show, if left too long, needs and behaviours can advance to the point that even LTCHs will not accept individuals into care, resulting in distressing situations for people and making stubborn health system problems such as elevated hospital ALC rates all the more difficult to solve.

Recommendation 2. Strengthen the evidence base

Our second recommendation speaks to building and expanding the evidence base. This seems particularly important in a period when needs are growing and when policy-makers and planners have to make increasingly tough choices between contending demands for constrained health care resources.

As observed earlier, the qualitative stories add new depth and detail to the evidence about the design and impact of BSO initiatives on people, providers and the health care system. The stories provide rich accounts of what was done, for whom, by whom, and how, along with

[25] Ontario. Report of the Expert Group on Home and Community Care. Gail Donner, Chair. 2015. Accessed on-line, July 2018, at http://health.gov.on.ca/en/public/programs/lhin/docs/hcc_report.pdf .
[26] Health Quality Ontario. The Reality of Caring: Distress among the caregivers of home care patients. 2016. Accessed on-line, September 2018, at http://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf

impact and lessons learned. They also expand the scope of previous evaluations by documenting BSO initiatives in the community and in hospitals as well as in LTCHs.

Of course, the stories also provide insight into the difficulties inherent in proving, in a clinical sense, that BSO investments offer comparable or greater value than investments in other health care priorities. In spite of the quality and appropriateness of the care provided, persons with responsive behaviours will most likely continue to decline albeit at a slower pace and with greater wellbeing and quality of life than might otherwise be expected. Moreover, BSO initiatives characteristically address complex needs and behaviours using non-standardized combinations of approaches, making it difficult to demonstrate causality.

Nevertheless, the qualitative stories point to many credible indicators of impact. In addition to change in behavioural symptoms among LTCH residents, the BSO legacy measure, they highlight more widely distributed benefits such as a greater willingness and ability on the part of care partners to continue to provide day-to-day care; more manageable workloads and greater work satisfaction for staff in hospitals and LTCHs; and lessened reliance on emergency services, hospital admissions and LTCH crisis relocations.

Leveraging the qualitative stories methodology, we suggest a multi-pronged approach to strengthening the evidence base.

First, BSO should continue to collect LHIN qualitative stories since these offer rich “front line” perspectives on challenges now being faced at the local level across the province, as well as innovative approaches to addressing them. This is valuable intelligence for health planners, providers and policy-makers.

Second, in addition to the information currently being provided, LHINs can be encouraged to identify key performance indicators to measure the impact of approaches recounted in the stories. From the LHIN perspective, what measures should be used to demonstrate impact?

Third, frequently occurring indicators can be compiled by BSO and communicated back to the LHINs for their review, feedback and revision. One way of doing this may be in the form of a “dashboard” presenting easy-to-understand graphics; graphics can have embedded links to more detailed data, where available, to support analysis. Such a dashboard might integrate the following:

- Measures of individual-level impact such as length of time a person with responsive behaviours can remain in the community after being assessed as eligible for a LTCH bed, as well as hours of informal care and caregiver distress

- Measures of organization impact such as staff satisfaction, retention, and the presence of a transitional care plan prior to admission

- Measures of system-level impact such as numbers of referrals to BSO, instances of inter-disciplinary, inter-organizational teamwork, avoided 911 calls and ER admissions, and refusals of care.

Ideally, although beyond the scope of our qualitative review, this approach will also stimulate progress toward the collection and analysis of standardized assessment data for BSO clients. While such assessments are now commonly conducted in home and community, hospitals and LTCHs across the province, evaluations to date have been hampered by the fact that data sets do not yet allow for the identification of BSO clients.

Recommendation 3. Advance knowledge mobilization and capacity building

Our third recommendation speaks to the importance of putting evidence and information into the hands of those who can best use it to build capacity at the local level and encourage the scale and spread of successful initiatives across the province.

The qualitative stories suggest that many providers are highly motivated to "know what others are doing." They want to learn about new ideas and innovative approaches to create more effective, person-centred care for their clients.

The stories also provide numerous examples of activities that advance knowledge mobilization and capacity building. Team meetings, "staff huddles" and staff education are reported to improve confidence and willingness to take on new challenges and go that extra step. Education around such approaches as P.I.E.C.E.S and Montessori are seen to have positive outcomes for care partners and formal providers alike. Inter-disciplinary, inter-organizational teams promote the transmission of specialized knowledge across traditional boundaries. Expert consultants, best practice forums, on-line seminars, and educational events can spur knowledge translation and build capacity.

However, while suggesting the value of such activities, the qualitative stories do not give a good sense of how frequently they occur or the extent to which providers are actually aware of innovations occurring even in their own backyards.

Here, BSO can play an important role. The re-emergence of the Provincial Coordinating Office (PCO) has already stimulated a range of activities aimed at gathering data and strengthening knowledge translation and communications.[27]

One approach may be to encourage the development of formal knowledge translation and mobilization plans at provincial and LHIN levels as an integral part of BSO activities. It is worth noting that leading health care research funding agencies (such as the Canadian Institutes of Health Research) now require investigators to develop such plans at the outset of their work to ensure that new knowledge generated is widely communicated to those who can use it.

[27] Behavioural Supports Ontario, Provincial Coordinating Office. Annual Report 2015-16. Accessed on-line, August 2018, at http://brainxchange.ca/Public/Files/BSO2/BSO-PCO-Annual-Report-2015-16.aspx

Other approaches, often featured in such plans, include the use of conventional as well as novel venues for knowledge exchange. Given the richness of the information contained in the qualitative stories, there would seem to be considerable value in ongoing communication of insights through regular e-newsletters, blogs or interactive on-line seminars with options for connecting individuals who want to learn more from each other.

Of course, when thinking about knowledge mobilization and capacity building, the needs and perspectives of care partners should not be overlooked. As the qualitative stories emphasize, care partners make essential and ongoing contributions to the care of persons with responsive behaviours in settings across the care continuum; without them, the formal care system would have to fill ever-widening gaps. The stories also show that tailored information, education and counselling can build caregiver resilience and capacity while relieving feelings of guilt and helplessness; care partners are uniquely positioned to say what knowledge is most important for them and how they would like to receive it.

Similarly, the lived experience of care recipients is increasingly acknowledged as a legitimate and valuable element of effective, person-centred care.[28] Thinking more about how knowledge and education can prepare individuals for what lies ahead, and how, in turn, their experiences can inform future care innovations, seems an important path to follow.

[28] See, for example, Health Quality Ontario. Patient and Caregiver Engagement at Health Quality Ontario. 2016. Accessed on-line, August 2018, at https://www.fco.ngo/sites/default/files/Patient%20and%20Caregiver%20Engagement%20at%20Health%20Quality%20Ontario.pdf