Behavioural Supports Ontario (BSO): Meeting New Challenges in the Time of COVID-19

Full Report

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Executive Brief Available

An Executive Brief summarizing key findings from this Full Report is available on-line at https://www.behaviouralsupportsontario.ca/

List of Acronyms Used in This Report

ABI	Acquired Brain Injury	**LGBTQ+**	Lesbian, Gay, Bisexual, Transgender & Queer Community
ACBC	Acute Care Behavioural Consultant	**LHIN**	Local Health Integration Network
ADL	Activities of Daily Living	**LTC**	Long-Term Care
ADOC	Assistant Director of Care	**MI**	Myocardial Infarction
ADP	Adult Day Program	**MD**	Medical Doctor
ALC	Alternate level of care	**MMSE**	Mini Mental State Exam
ASH	Addictions Supportive Housing	**MOHLTC**	Ministry of Health and Long-Term Care
BPSD	Behavioural and Psychological Symptoms of Dementia	**MP**	Member of Parliament
BSO	Behavioural Supports Ontario	**NP**	Nurse Practitioner
BSOT	Behavioural Support Outreach Team	**OCD**	Obsessive-Compulsive Disorder
CAMH	Centre for Addictions & Mental Health	**OECD**	Organization for Economic Co-Operation and Development
CGA	Comprehensive Geriatric Assessment	**OHA**	Ontario Hospital Association
CIHI	Canadian Institute of Health Information	**OPP**	Ontario Provincial Police
COT	Community Outreach Team	**OT**	Occupational Therapist
CRO	Coordinating & Reporting Office	**OTN**	Ontario Telemedicine Network
CSW	Community Support Worker	**PCO**	Provincial Coordinating Office
DOS	Dementia Observation System	**PEC**	Public Education Coordinator
DM	Diabetes Mellitus	**PERT**	Personal Expressions Resource Team
ED	Emergency Department	**POA**	Power of Attorney
EMS	Emergency Medical Service	**PRC**	Psychogeriatric Resource Consultant
ENDS	Electronic Nicotine Delivery System	**PSW**	Personal Support Worker
GBA+	Gender-Based Analysis Plus	**PT**	Physiotherapist
GEM	Geriatric Emergency Medicine	**RN**	Registered Nurse
GERD	Gastroesophageal Reflux Disease	**RPN**	Registered Practical Nurse
GMHOT	Geriatric Mental Health Outreach Team	**SST**	Specialized Social Therapist
GPA	Gentle Persuasive Approaches	**TIA**	Transient Ischemic Attack
HQO	Health Quality Ontario	**UTI**	Urinary Tract Infection

1.0 Introduction

Behavioural Supports Ontario (BSO) provides behavioural healthcare for older adults living with, or at risk of, responsive behaviours/personal expressions associated with dementia, complex mental health, substance use and/or other neurological conditions, along with care partners, in community, hospital and residential long-term care (LTC) settings.[1]

Although increasingly understood as an expression of unmet needs, behaviours/expressions such as repetitive questioning, pacing, cursing, screaming, hitting, pushing and exploring/searching[2] can nonetheless impact negatively on persons expressing them, as well as care partners, providers, others living in congregate settings, and care systems.[3]

This report is the third in a series commissioned by the BSO Provincial Coordinating Office (PCO).

In our first report[4] we provided an introduction to BSO and its evolution. Rather than being created as a singular intervention at a particular point in time, BSO emerged over two decades as a framework for new and existing initiatives aimed at enhancing care for persons with behaviours/expressions and care partners. Evaluation results revealed numerous positive outcomes associated with BSO work including "measurable change to health service delivery culture and provider mix" and a "renewed focus on quality improvement." As well, lower hospitalization rates were observed for residents supported by BSO in LTC homes in some regions;[5] BSO teams in these homes reported enhanced point-of-care education, staff assessment and management of behaviours/expressions, resulting in improved care and outcomes.[6]

In our second report[7] we analyzed 253 "qualitative stories" from Ontario's 14 Local Health Integration Networks (LHINs) between 2015 and 2018. These stories offered detailed "real

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[1] Behavioural Supports Ontario. About Us. Accessed on-line, February, 2021 at https://www.behaviouralsupportsontario.ca/29/Background/

[2] Behavioural Supports Ontario. What is Behavioural Change? Accessed on-line, January 2021, at https://www.behaviouralsupportsontario.ca/32/Behaviour_Change_in_Older_Adults/

[3] Alberta Health Services. Responsive Behaviours. Accessed on-line, February 2021, at https://www.albertahealthservices.ca/assets/about/scn/ahs-scn-srs-responsive-behaviours.pdf

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

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

[6] 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

[7] Morton-Chang F, Williams AP. 2018. Behavioural Supports Ontario: Review of Qualitative Stories. Accessed on-line, February, 2021at https://behaviouralsupportsontario.ca/Uploads/ContentDocuments/2019-07_BSO_Review_of_Qualitative_Stories.pdf

world" insights into the design and impact of BSO initiatives in community, hospital and LTC settings. We identified eight recurrent themes or dimensions in the stories documenting the needs and characteristics of persons receiving BSO support, approaches used to provide support, and outcomes at individual, organization and system levels. The report offered three main recommendations to guide BSO work: reaffirm person-centred care as a core value; strengthen the evidence base; and advance knowledge mobilization and capacity building.

In this third report we draw on multiple, complementary evidence sources to dig deeper into the work and impact of BSO prior to and during the COVID-19 pandemic. These include:

- Two hundred and sixty-nine qualitative stories written by BSO teams across Ontario between the first quarter of 2018 (where our previous analysis left off) and the second quarter of 2020 (when the pandemic was already well under way)
- Key Informant interviews with 20 BSO team members and collaborators from all regions of the province, different care settings (e.g., community, hospital, residential care), and diverse professional/occupational groups (e.g., Physicians, Nurses, Personal Support Workers) conducted in late 2020 and early 2021
- Findings from a Lived Experience forum and individual interviews involving a total of 13 persons living with dementia and care partners conducted in the spring of 2021.

In the sections below we begin by outlining the demographic and policy context for BSO work and this report. We then detail "what we did" (e.g., evidence sources and methods) and "what we found" (e.g., results from the qualitative stories, Key Informant interviews and Lived Experience forum and individual interviews). We conclude with three recommendations to inform BSO work going forward.

It is worth noting, even at this early juncture, that in spite of the extraordinary demands of the pandemic, and the different perspectives represented in each of these three evidence sources, a strong and consistent message emerged: in a period of rising and more complex needs, and care systems that struggled to meet needs even prior to the pandemic, the work of BSO and its readiness to take on the most complex challenges at individual, organization and systems levels, seem all the more essential. The real question, from provider and Lived Experience perspectives alike, is how to scale and spread this work.

2.0 A Brief History of BSO

As summarized in our first report,[8] the roots of BSO date back to the mid-1990s when it was already well understood that the population was aging, that the number of older Canadians living with dementia was rising, and that the costs and consequences would be widespread and profound particularly if action was not taken.

In 1999, Ontario introduced a four year, $68.4 million Strategy for Alzheimer Disease and Related Dementias, a wide-ranging plan that anticipated a mix of educational programs, service enhancements in community and residential care settings, along with research activities and knowledge exchange.[9] This strategy also saw the development of dedicated positions called psychogeriatric resource consultants (PRCs) to support learning in LTC homes, along with public education coordinators (PECs) at local Alzheimer Societies to support learning in the community. Nevertheless, in 2003, the provincial strategy lapsed, and while some initiatives remained, many were left to find their own funding after a transition period ending in 2007.

At about the same time, issues around responsive behaviours/personal expressions became more visible. In 2007, Ontario's Ministry of Health and Long-Term Care (MOHLTC) released a report titled *Building a Better System: Caring for Older Individuals with Aggressive Behaviours in Long-Term Care Homes*. This report, a response to a Coroner's Inquest investigating the tragic death of two LTC residents killed by a new resident, highlighted a growing need for prevention, knowledge, coordination, integration, early identification and adequate supports to safely manage residents living with behaviours/expressions.[10]

In 2009, a knowledge exchange session with multiple stakeholders was convened by the Alzheimer Knowledge Exchange, Alzheimer Society Ontario, MOHLTC and the North Simcoe Muskoka Local Health Integration Network (LHIN). Consensus was reached on the need to build a shared model of behavioural supports with the goal of implementing an integrated system approach to the care for those living with behaviours/expressions.

In 2010, Ontario announced the development of an evidence and experience-based framework to enhance the availability of supports and services to persons living with responsive

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[8] Morton-Chang F, Williams AP. 2018. Behavioural Supports Ontario: Review of Evaluation Outcomes. Submitted to Behavioural Supports Ontario provincial Coordinating Office.

[9] Morton-Chang F. 2015. Tipping points to institutional care for persons living with dementia: analyzing the policy trajectory in Ontario. PhD. Thesis, Institute of Health Policy, Management and Evaluation, University of Toronto, 2015. Accessed, on-line, March 2018, at https://tspace.library.utoronto.ca/bitstream/1807/69351/3/Morton-Chang_Frances_M_201506_PhD_thesis.pdf

[10] Dudgeon, S. and Reed, P. 2010. Older Adults Behavioural Support System. Accessed on-line, March 2018, at http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-Support-System.aspx

behaviours/personal expressions.[11] A Framework for Care was developed including "three pillars:" system coordination and management through cross-agency, cross-sectoral collaboration and partnerships; inter-disciplinary service delivery across the continuum to ensure equitable and timely access to the right provider for the right services; and knowledgeable care teams equipped with best practice skills.[12] The "regional" character of the program was emphasized; while working from common principles, LHINs would implement approaches suited to local needs and resources.[13]

Behavioural Supports Ontario (BSO) was built on these pillars. By early 2012, all 14 LHINs had adopted the Framework for Care and a provincial Coordinating and Reporting Office (CRO) was created to coordinate LHIN-based initiatives and ensure fiscal accountability until March 2013.

A BSO provincial coordinating office re-emerged in 2015; it is now hosted at the North Bay Regional Health Centre. Subsequently, the MOHLTC (now Ministry of Long-Term Care [MLTC] and Ministry of Health [MOH]), made new investments to scale and spread BSO. The primary goal of this funding was to ensure that all Ontario LTC Homes had access to specialized behavioural support teams.

BSO resources in the community and acute care received dedicated funding through the Ontario Dementia Strategy over the period of 2017-20, including funds to establish and/or enhance BSO centralized intake mechanisms.

What has changed since BSO's inception?

On the demand side, population needs have continued to rise in volume and complexity. In 2018, an estimated half a million Canadians lived with dementia; by 2023 that number is expected to double[14] as Canadians live longer and the risks of dementia and related neurocognitive conditions increase with age.[15] [16] Added to this, findings from the 2017 Commonwealth survey suggest that a third of Canadian seniors live with at least 3 chronic

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[11] Behavioural Supports Ontario. About Us. Accessed on-line, February, 2021 at https://www.behaviouralsupportsontario.ca/29/Background/

[12] Behavioural Supports Ontario. 2017. Behavioural Supports Ontario (BSO) Initiative Overview.

[13] Dudgeon, S. and Reed, P. 2010. Older Adults Behavioural Support System. Accessed on-line, March 2018, at http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-Support-System.aspx

[14] Alzheimer Society Canada. 2018. Latest information and statistics. Accessed on-line, September 2020, at https://alzheimer.ca/en/Home/Get-involved/Advocacy/Latest-info-stats

[15] Canadian Institute for Health Information. How dementia impacts Canadians. Accessed on-line, February 2021 at https://www.cihi.ca/en/dementia-in-canada/how-dementia-impacts-canadians

[16] Morton-Chang F, Williams AP, Berta W, Laporte A. 2019. Towards a community-based dementia care strategy: how do we get there from here? World Health and population 18(1): 6-29. Accessed on-line, February 2021 at https://www.longwoods.com/content/26062//towards-a-community-based-dementia-care-strategy-how-do-we-get-there-from-here-

conditions, while 14% face a mental health challenge such as depression or anxiety.[17] For community-dwelling persons living with dementia in Ontario, numbers are higher. It is estimated that more than three quarters (77%) experience six or more comorbidities; these persons are also almost twice as likely to be hospitalized as those living without dementia.[18]

Although limited, available evidence suggests that responsive behaviours/personal expressions are also on the rise. Estimates suggest that 50-90% of Canadians living with dementia may be at risk of developing "behavioural or psychological symptoms."[19]

While affecting people across the care continuum, behaviours/expressions are particularly visible in LTC homes. A 2011 Canadian study showed that between 26% and 66% of individuals in care homes recorded some form of "aggressive behaviour" including "verbal and physical abuse, socially inappropriate behaviour, and resisting care."[20] A 2018 review concluded that 90% of Ontario LTC residents live with some form of cognitive impairment and that most (80%) will exhibit "behavioural symptoms of dementia" at some point during the "course of their disease."[21]

On the supply side, care systems continue to struggle. Prior to the COVID-19 pandemic, Health Quality Ontario (HQO) noted there had been improvements in health care in discrete areas like wait times for cancer care and the use of electronic communications between patients and providers. Nevertheless, persistent and costly problems remained, key among them the difficulties faced by growing numbers of persons with multiple health needs attempting to access different areas of care. While trying to navigate on their own, these persons could "fall through the cracks" and "get stuck" for extended periods in inappropriate care settings such as

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[17] Canadian Institute for Health Information. 2018. How Canada Compares: Results from the Commonwealth Fund's 2017 International Health Policy Survey of Seniors. Accessed on-line, June 2021, at https://www.cihi.ca/en/commonwealth-fund-survey-2017

[18] Bronskill SE, Yates E, Guan J, Walker J, Newman A, Wang X, Vermeulen M. 2020. AHRQ Report: Health system utilization patterns of community-dwelling persons with physician-diagnosed dementia in Ontario. Toronto, ON: Institute for Clinical Evaluative Sciences; Jan 2016

[19] Baycrest. What are responsive behaviours? Accessed on-line, June 2021, at https://www.baycrest.org/Baycrest/Education-Training/Educational-Resources/Responsive-Behaviours/What-are-responsive-behaviours

[20] Perlman C, Hirdes J. 2008. The Aggressive Behavior Scale: A new scale to measure aggression based on the Minimum Data Set. Journal of the American Geriatrics Society, 56(12), 2298–2303. Accessed on-line, June 2021, at https://psycnet.apa.org/record/2008-18152-017

[21] Ontario Long Term Care Association. 2018. This is Long-Term Care 2018., at https://www.oltca.com/OLTCA/Documents/Reports/Thisislongtermcare2018.pdf

acute care hospital beds, thus contributing to the costly and persistent problem of "hallway medicine."[22] [23]

According to the Premier's Council on Improving Healthcare and Ending Hallway Medicine, "on an average day in 2018, there were approximately 1,000 patients waiting for a hospital bed in an unconventional space or emergency department stretcher;" many of these were older persons living with dementia and other chronic conditions whose needs surpassed available LTC capacity, resulting in delayed admissions and additional strain on families.[24]

This aligns with evidence that persons living with dementia are two to five times more likely than other adults to use home care, hospital emergency departments (EDs), in-patient hospital beds, hospital ALC (Alternative Level of Care) beds and LTC, and to experience negative outcomes.[25] Moreover, persons living with dementia are more likely than others to require ongoing and specialized care due to confusion, anxiety, agitation and delirium and they typically stay longer in hospital than their peers. The Ontario Hospital Association (OHA) has identified the need for "enhancing behavioural support capacity in long-term care and community settings" as crucial to "ending hallway medicine."[26]

The COVID-19 pandemic layered on new challenges. While dementia "does not increase risk for COVID-19," "people with Alzheimer's disease and other dementia may forget to wash their hands or take other recommended precautions to prevent illness."[27] As the recent report of Canada's Chief Public Health Officer of Canada's observed[28] the pandemic's impact has been most severe among communities characterized by "overlapping and compounding risks related

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[22] Health Quality Ontario. Measuring Up 2019. Accessed on-line, February 2021, at https://www.hqontario.ca/System-Performance/Yearly-Reports/Measuring-Up-2019

[23] Ontario Hospital Association. 2019. A Balanced Approach: The Path to Ending Hallway Medicine for Ontario Patients and Families. Pre-Budget Submission 2019 Ontario Budget. Accessed on-line, February 2021, at https://www.oha.com/Bulletins/A%20Balanced%20Approach%20-%202019%20Pre-Budget%20Submission.pdf

[24] Premier's Council on Improving Healthcare. 2019. Hallway Health Care: A System Under Strain. 1st Interim Report from the Premier's Council on Improving Healthcare and Ending Hallway Medicine. Accessed on-line, February 2021, at https://files.ontario.ca/moh-hallway-health-care-system-under-strain-en-2019-06-24.pdf

[25] Morton-Chang F, Williams AP, Berta W, Laporte A. 2019. Towards a community-based dementia care strategy: how do we get there from here? World Health and population 18(1): 6-29. Accessed on-line, February 2021 at https://www.longwoods.com/content/26062//towards-a-community-based-dementia-care-strategy-how-do-we-get-there-from-here-

[26] Ontario Hospital Association. 2019. A Balanced Approach: The Path to Ending Hallway Medicine for Ontario Patients and Families. Pre-Budget Submission 2019 Ontario Budget. Accessed on-line, February 2021, at https://www.oha.com/Bulletins/A%20Balanced%20Approach%20-%202019%20Pre-Budget%20Submission.pdf

[27] Alzheimer Society Canada. 2020. Coronavirus (COVID-19): Tips for dementia caregivers. Accessed on-line, September 2020, at https://alzheimer.ca/sites/default/files/files/coronavirus%20tips%20for%20dementia%20caregivers.pdf

[28] Chief Public Health Officer of Canada. 2020. From risk to resilience: an equity approach to COVID-19. Report on the State of Public Health in Canada 2020. Accessed on-line, March 2021 at https://www.canada.ca/en/public-health/corporate/publications/chief-public-health-officer-reports-state-public-health-canada/from-risk-resilience-equity-approach-covid-19.html#a2.1

to sex, gender, racialization, income, housing, employment, and other socioeconomic factors" including older Canadians.[29]

In the community, financial stress, lockdowns and service disruptions intensified social isolation and made essential everyday tasks such as grocery shopping and attendance at medical appointments more difficult even as access to formal supports such as adult day programs was curtailed. Limited access to needed health and social care including in-home help and respite increased burden and stress for care partners. Studies from the United States point to a significant increase in elder abuse after the beginning of the pandemic.[30] [31]

In hospitals, infection control measures, while aimed at limiting disease spread, disrupted many services. A temporary freeze on LTC bed placements in Ontario, also aimed at limiting disease spread, meant that hospitalized older persons living with dementia were "stuck" in hospital beds for extended periods with consequent declines in mental and physical health.[32]

COVID's deadliest toll has been in LTC homes.[33] In June 2020, just months after the pandemic had become widespread in Canada, the Canadian Institute of Health Information (CIHI) estimated that more than 5,300 LTC residents had died of COVID, accounting for 81% of all COVID deaths in Canada, almost twice the OECD (Organization for Economic Cooperation and Development) average of 42%.[34] [35] During the pandemic's second wave, COVID infections among residents of LTC and retirement homes actually increased by two thirds.[36]

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[29] Government of Canada. 2020. Vulnerable populations and COVID-19. Accessed on-line, September 2020, at https://www.canada.ca/en/public-health/services/publications/diseases-conditions/vulnerable-populations-covid-19.html

[30] Makaroun LK, et al. Elder Abuse in the Time of COVID-19—Increased Risks for Older Adults and Their Caregivers. Am J Geriatr Psychiatry. 2020 Aug; 28(8): 876–880. Accessed on-line, September 2020, at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7234937/

[31] Han SD, Mosqueda L. 2020. Elder Abuse in the COVID-19 Era. Journal of the American Geriatrics Society. 68(7): 1386-1387. Accessed on-line, September 2020, at https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.16496

[32] Ontario Health Coalition. 2020. COVID-19 Update. Accessed on-line, September 2020, at https://www.ontariohealthcoalition.ca/wp-content/uploads/Outbreaks-July-13-final.pdf

[33] Chief Public Health Officer of Canada. 2020. From risk to resilience: An equity approach to COVID-19. Accessed on-line, February 2021, at https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf

[34] Canadian Institute for Health Information. 2020. CIHI. Pandemic Experience in the Long-Term Care Sector. Accessed on-line, September 2020, at https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf

[35] Canadian Institute for Health Information. 2020. CIHI. Pandemic Experience in the Long-Term Care Sector. Accessed on-line, September 2020, at https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf

[36] Canadian Institute for Health Information (CIHI). 2020. Pandemic Experience in the Long-Term Care Sector. How Does Canada Compare With Other Countries? Ottawa, ON. Accessed on-line, June 2021, at https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf

Moreover, even in homes where no outbreaks occurred, the pandemic often resulted in severe restrictions on the movement of LTC residents and visits by care partners.[37] [38] Such restrictions, combined with worker shortages, appear to have contributed to a sharp rise in the use of antipsychotics, antidepressants, sleeping medications and benzodiazepines. Between March and September 2020 the use of such drugs in 263 LTC residences in Ontario increased significantly, despite a growing body of evidence that they can increase the "risk of stroke, falls and all-cause mortality, and are not recommended for frail, older adults," including persons living with dementia, "who make up about 70 per cent of LTC residents in Ontario."[39]

In sum, BSO operates in a dynamic and challenging environment characterized by rising and more complex population needs and care systems that struggled even prior to the pandemic. As such, BSO work presents as a classic case of "complexity" in healthcare, where there are so many interacting parts that it is difficult to separate them out.[40]

In the sections below, we begin by detailing "what we did" and then "what we found." We then summarize key findings and offer recommendations for the future.

3.0 What We Did

We analyzed multiple evidence sources and then "triangulated" the results. Triangulation is commonly used in social research and evaluation, to widen and deepen understanding of complex subjects by examining them from different perspectives.[41]

In doing this, we were interested in assessing both the current work and impact of BSO, and what, if anything, had changed since our 2018 reports. Accordingly, in our presentation of the findings of the qualitative stories, we begin each section by briefly reviewing what we found in 2018 before presenting findings from the more recent stories. Likewise, in the results of the Key

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[37] Ontario, Ministry of Long-Term Care. 2020. Update to visits at long-term care homes. Accessed on-line, September 2020, at http://www.health.gov.on.ca/en/pro/programs/ltc/docs/covid-19/mltc_resuming_ltc_home_visits_20200715.pdf

[38] Welsh M. 2021. Nursing home residents sick with COVID kept out of hospital far more than seniors in community. Inside the documents, data and attitudes that explain why. Tuesday, February 9. Accessed on-line, February 2021, at https://www.thestar.com/news/investigations/2021/02/09/nursing-home-residents-sick-with-covid-kept-out-of-hospital-far-more-than-seniors-in-community-inside-the-documents-data-and-attitudes-that-explain-why.html

[39] Alkenbrack K. 2020. Doctors concerned about rise in dangerous medications in long-term care homes during pandemic. CTV News. December 3. Accessed on-line, February 2021, at https://www.ctvnews.ca/health/doctors-concerned-about-rise-in-dangerous-medications-in-long-term-care-homes-during-pandemic-1.5215060

[40] World Health Organization. Systems and the effect of complexity on patient care. Accessed on-line, February 2021, at https://www.ctvnews.ca/health/doctors-concerned-about-rise-in-dangerous-medications-in-long-term-care-homes-during-pandemic-1.5215060

[41] Olsen W. 2004. Triangulation in social research: Qualitative and quantitative methods can really be mixed. Accessed on-line, February 2021, at https://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/COVID-19.aspx#4a

Informant interviews and Lived Experience Forum and interviews, we highlight the extent to which Respondents perceive change in both needs and system responses.

3.1 Qualitative Stories

The first evidence source consists of 269 qualitative stories written by BSO teams across the province between the first quarter of 2018/19 and the second quarter of 2020/21 (see Table 1). These stories, consisting of detailed, first-hand accounts of real-life events, are submitted to the BSO PCO on a quarterly basis.

Table 1. Distribution of Qualitative Stories By Year and Quarter

Year & Quarter	**Number of Qualitative Stories**
2018/19 Q1	25
2018/19 Q2	26
2018/19 Q3	34
2018/19 Q4	35
Sub-Total	120
2019/20 Q1	26
2019/20 Q2	31
2019/20 Q3	26
2019/20 Q4	19 (pandemic period)
Sub-Total	102
2020/21 Q1	22
2020/21 Q2	25
Sub-Total	47
Total	**269**

To ensure comparability, we applied the same analytic method used in our 2018 analysis. The consultants (A. Paul Williams and Frances Morton-Chang), both trained and experienced qualitative researchers and evaluators, independently reviewed and coded each of the qualitative stories to identify recurring themes and dimensions; they then cross-checked results to identify areas of convergence and reconcile differences.

3.2 Key Informant Interviews

The second evidence source consists of semi-structured interviews with 20 BSO team members and collaborators asking about their experiences in day-to-day practice.

Key Informants were selected by the consultants from a pool of 43 “volunteers” provided by the BSO PCO. All individuals in the pool either worked in BSO roles (e.g., as BSO Leads in LTC homes, hospitals and community settings) or in collaborating organizations (e.g., local Alzheimer Societies, community mental health agencies).

A "maximum variation" sampling strategy was used to ensure broad representation along three key dimensions:

- Region: approximately equal numbers were selected from each of Ontario's 5 Health Regions (i.e., West, Central, Toronto, East, North), with representation, where possible, from at least 2 different LHINs within each Health Region (e.g., Erie St. Clair, South West, Hamilton Niagara Haldimand Brant and Waterloo Wellington LHINs within the West Health Region)
- Sector: approximately equal numbers from LTC and "other" sectors (e.g., community, acute care)
- Profession/occupation: physicians, nurses, therapists, geriatric services managers, personal support workers, educators, and team leads.

To protect confidentiality and encourage forthright responses, the BSO PCO was not told which individuals were selected or interviewed. Key Informants were assured that while their responses would be reported, and quotes used where appropriate, they would not be identified in any report or presentation of the results.

Of the 20 Key Informants selected by the consultants, 19 (95%) were interviewed. For work-related reasons, one individual was not available. However, an interview was conducted with a co-worker substituting to produce an overall completion rate of 100%. Table 2 shows the distribution of Key Informants interviewed by Health Region and sector.

Table 2: Distribution of Key Informants by Health Region and Sector [1]

Health Region/Sector	**LTC**	**Other Sectors** [2]	**Total**
West	3	2	5
Central	1	2	3
Toronto	2	2	4
East	2	2	4
North	1	3	4
Total	9	11	20

[1] Including physicians, geriatric psychiatrists, RNs, RPNs, NPs, social workers, PSWs, educators, geriatric team leads, directors of care, psychogeriatric resource consultants, managers

[2] Including community, acute care hospitals, cross-sector and mobile teams

Using an open-ended approach, Key Informants were asked for their insights in three broad areas:

- Demand and supply-side trends and issues prior to and during the pandemic
- Emerging best practices and lessons learned

- Opportunities for spreading and scaling the work of BSO.

All interviews were conducted via Zoom and lasted 30-45 minutes. With the expressed consent of Key Informants, interviews were recorded solely for the purpose of verifying the interviewers' field notes.

As with the results of the qualitative stories, the two consultants independently reviewed and coded interview transcripts and then cross-checked the results.

3.3. Lived Experience Forum and Interviews

The third evidence source documents the perspectives of persons with lived experience, including care partners. While recognizing important ethical cautions around privacy, informed consent, and recruitment,[42] engaging those with "lived experience" is increasingly seen as crucial to elaborating and validating research and evaluation findings, affirming the "personhood" of individuals using care, and improving care processes and outcomes.[43] To facilitate participation, two alternatives were offered: an on-line group "forum" and individual interviews.

Lived Experience Forum. A 90 minute on-line forum with a total of eight persons living with dementia and care partners was held in late March 2021. To recruit Respondents, members of the BSO Provincial Lived Experience Advisory[44] were contacted by two BSO Lived Experience Co-Facilitators (one a person living with dementia and the other a care partner), given a short overview of the evaluation project written by the consultants, and invited to participate in the forum. To protect confidentiality, the identities of Respondents were not revealed to the BSO PCO.

The forum agenda was co-created in collaboration with the BSO Lived Experience Co-Facilitators. To prompt discussion, Respondents were presented with a brief overview of the evaluation project and then asked to comment on draft findings and recommendations. To add a measure of safety, a BSO team member trained to support individuals living with dementia and care partners remained "on call" for the duration of the forum in the event that any participant experienced distress.

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[42] West E, Stuckelberger A, Pautex S, Staaks J, Gysels M. 2017. Operationalising ethical challenges in dementia research—a systematic review of current evidence. *Age and Ageing*, Volume 46, Issue 4, July 2017, Pages 678–687. Accessed on-line, February 2021, at https://academic.oup.com/ageing/article/46/4/678/2926037

[43] Gorska S, Forsyth K, Maciver D. 2018. Living with dementia: A meta-synthesis of qualitative research on the lived experience. Gerontologist 2018;58:e180-e196. Accessed on-line, February 2021, at https://pubmed.ncbi.nlm.nih.gov/28069886/

[44] Behavioural Supports Ontario. (ND). Behavioural Supports Ontario Provincial Lived Experience Network Advisory. Accessed on-line, April 2021 at https://brainxchange.ca/Public/Files/Lived-Experience-Advisory-Network/ODSFeedback_BSO-Lived-Experience-Network-Advisory.aspx

With the consent of all Respondents, forum proceedings were recorded solely for the purpose of accurately reporting the results. Respondentss were assured that while comments and quotes would be used, individuals would not be identified in any report or presentation of the results. Transcripts of the proceedings were reviewed and coded by each of the consultants independently, and then cross-checked to ensure accuracy.

Lived Experience Interviews. In April 2021, five 30 minute on-line interviews were conducted with persons living with dementia and care partners who did not attend the forum. Once again, Respondents were recruited with the assistance of the BSO Lived Experience Co-Facilitators; identities were not revealed to the BSO PCO.

Interviews were semi-structured, focusing on personal experiences with BSO and other care providers. Respondents offered rich descriptions of their care journeys including challenges they had experienced when trying to access care.

With the consent of Respondents, interviews were recorded solely for the purpose of accurately reporting the results. Interview transcripts were subsequently reviewed and coded by each of the consultants independently, and then cross-checked to ensure accuracy.

4.0 What We Found

In this section, we present findings from each of the three evidence sources in turn: the qualitative stories, Key Informant interviews and Lived Experience forum and interviews. As noted earlier, we highlight changes since 2018.

4.1 Qualitative Stories

In our 2018 report, we identified eight recurrent themes/dimensions in the qualitative stories. These were:

1. Responsive behaviours/physical expressions (e.g., depression, refusal to accept care)
2. Client needs (e.g., health and social needs)
3. Initial point of BSO contact (e.g., community, hospital, LTC)
4. Involved providers (e.g., health and social care providers)
5. Transitions (e.g., between community, hospital and LTC settings)
6. BSO initiatives (e.g., at individual, organization or system levels)
7. Outcomes and benefits (e.g., for individuals, providers, health care system)
8. Lessons learned (e.g., to inform future successes).

Based on our initial review of the more recent qualitative stories, we revised this classification. Specifically:

- We combined “Responsive Behaviours” and “Client Needs” into a single dimension titled “The Person.” This reflects a strong emphasis in the stories on the importance of seeing the whole person, including their characteristics, preferences, needs, and behaviours/expressions, to validate their personhood and provide person-centred care.

- We renamed the dimension titled "Involved Providers" to "Providers and Care Partners" reflecting the fact that care partners (including family, friends and neighbours), when present, invariably make valuable contributions to assessment, care planning and care delivery in community, hospital and LTC settings alongside, and in collaboration with, health and social care providers.
- We also identified two new dimensions:
    - "Balancing Pharmacological and Non-Pharmacological Approaches." This dimension recognizes frequent mentions in the more recent qualitative stories to initiatives aimed at moderating the use of drugs to manage responsive behaviours/personal expressions.
    - "New Challenges in the Time of COVID-19." This dimension highlights issues recorded during the extraordinary circumstances of the COVID-19 pandemic.

4.1.1 Dimension 1: The Person

This first dimension focuses on the person, including their characteristics, needs and responsive behaviours/personal expressions.

Behaviours/expressions are highly evident in the qualitative stories, not surprisingly, since they are at the focus of BSO's mandate. Nevertheless, as one story-writer observed, "behaviours don't define a person" (20-2-19). Seeing the whole person is the basis for person-centred care.

What We Found in 2018. In our 2018 report we recorded an extensive and varied list of behaviours/expressions including alcohol/tobacco/substance use, anxiety, collecting/hoarding, depression, exit seeking, hallucinations, mood changes, pacing, paranoia, resistance to care, self-neglect, verbal and physical expressions, sexual touching, wandering, withdrawal and self-harm.[45]

The stories clarified that although behaviours/expressions can present one-at-a-time, many individuals present with multiple behaviours/expressions that can change over time.

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[45] For a full list see section 3.3.1 in Morton-Chang F, Williams AP. 2018. Behavioural Supports Ontario: Review of Qualitative Stories. Accessed on-line, February, 2021at https://behaviouralsupportsontario.ca/Uploads/ContentDocuments/2019-07_BSO_Review_of_Qualitative_Stories.pdf

We also recorded a lengthy and diverse list of needs underlying behaviours/expressions. While all were associated with dementia, cognitive deficits, and/or mental health and addictions, they were often complicated by factors including:

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

What Changed? The stories since 2018 confirm that many/most persons supported by BSO experience "multimorbidity," that is, "the co-occurrence of multiple chronic or acute diseases and medical conditions in one person."[46] Moreover, as observed in 2018, such medical conditions are often compounded by physical, social and mental health challenges or trauma (e.g., sexual abuse, death of a loved one). For example:

- "This story is in relation to an 89 year old lady who has lived in LTC for the last 6 years. … She needs assistance with all ADLs [activities of daily living]. Her medical history includes: Delirium; Hypertension; mixed Dementia; Hx: falls; Bipolar disorder … Hyperlipidemia, recurrent UTIs [urinary tract infections] (E.coli), Hx. left hip fracture, and partially deaf. The resident used to have hearing aids but they were constantly missing, as the resident could not tolerate anything in her ears" (19-1-12)
- "… 84 year old female admitted to Long Term Care (LTC) home … from her daughter's house in the community. Diagnosis of mixed dementia (Alzheimer's & Vascular), Transient Ischemic Attacks (TIA), GERD [Gastroesophageal reflux disease], sleep apnea and asthma. This resident dealt with several losses. Subsequent to her admission to LTC home, her husband became very ill and passed away. She was no longer able to live on her own in the community and her condominium was sold and it was no longer possible for her dog to be with her at the LTC home 24/7 (her dog was previously a source of comfort for her but was starting to become difficult for her to manage)." (20-1-13)
- "… one of our residents expressed that he was feeling suicidal and felt there was no reason to go on living. … [he] has no children and was never married; his parent[s] both passed away and his contacts are good friends. He had an accident … causing a brain

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[46] Johnston M, Crilly M, Black C, Prescott GJ, Mercer SW. 2019. Defining and measuring multimorbidity: a systematic review of systematic reviews. European Journal of Public Health, Volume 29, Issue 1, February 2019, Pages 182–189. Accessed on-line, February 2021, at https://academic.oup.com/eurpub/article/29/1/182/5033670

injury … Prior to coming into long term care, our resident had been living in his [vehicle] …" (20-1-04)

Behaviours/expressions are similarly complex. They can be directed at others, including care partners, staff and other persons, or they can be directed inward through self-neglect, anxiety, depression and withdrawal.

- "…she began to exhibit attention seeking behaviour requesting to be toileted 2-3 times in an hour. Staff would try to reason with her and remind her that she had just been toileted recently. This caused the resident to become agitated, argumentative and scold the staff. After another few weeks passed the resident exhibited physical aggression, agitation, paranoia and began hoarding supplies she found [in] staff carts. She called 911 several times to report that staff was stealing her belongings." (19-1-17)
- "… upon initial admission, she desperately wanted to leave the facility to return home, making several attempts to do so. When she was unable to leave, she would cry and had become verbally and physically aggressive by hitting, kicking and punching doors. On one occasion, she hit another resident who was trying to help her, and another incident involved the resident leaving the facility and running towards a road where staff were able to intervene, and redirect her without incident." (19-2-15)
- "This resident is 77 years old married male; has Son and daughter; was admitted from [the] mental health unit. He was in the hospital for about 11 months for aggressive behaviours. He is alert and pleasant man, speaks only few words. He was a professional musician and is still able to play the piano which calms him down. … He is diagnosed with Alzheimer's, Dementia, BPSD [behavioural and psychological symptoms of dementia]. Resident is ambulatory with no gait aid, no history of falls. He needs limited to extensive assistance with his ADL's due to cognitive impairment. Expressive Behaviour: Wandering/exit seeking, attempting to enter co-resident's room, getting anxious and agitated by loud noises (during fire drill); verbally/physically expressive toward staff during care by yelling, pushing, hitting and refusing to have his clothes changed." (19-4-20)

While such complex needs and behaviours/expressions are most evident in stories recorded in LTC homes, they are also present in community and hospital settings where care partners, health and social care providers, first responders, local businesses and community neighbours, may require specialized support to respond appropriately.

- "Refusing assistance. He believes he is still able to live independently despite his cognitive and physical decline and difficulty coping at home. He often forgets to take his medications and usually skips a meal due to his dementia. He refuses to move to a retirement home or long term care home. … Paranoia believing that his daughter is controlling him … Suspicious that the bank is taking and controlling his money … Repeatedly contacting real estate agents and asking that they sell his house without planning for where he'll live after the house sells. … Verbally aggressive with bank staff and managers as he wanted to withdraw all his money." (19-1-15)

- "Wife's main concerns: He is unmotivated, "stubborn", will not help out around the home. … So frustrated with him that she limits engaging with him. Asked him to move to basement. … Missing mortgage payments. Used to have a joint account with patient however 6 months ago he transferred all of his money out of the account and opened a new one. Wife states funds are tight. … Wife would like him to go to an ADP [adult day program] however he does not want to pay for it with his money. … Easily agitated and irritable. Delusions regarding family's activities. …He is non-adherent with all of his medications (longstanding). Limited insight into indications for his medications. ….Patient told wife he met with his cardiologist and that some of his medications were stopped. …Believes he is behaving this way by choice. "Too young to have dementia". (19-2-17)
- "The patient is a 78 year old female who was admitted to hospital with an increase in behaviours. The patient is deaf and communicates with interpreters, but uses a lot of slang, at one point requiring two interpreters for communication. For approximately three weeks, she was leaving her apartment at night, and knocking on car windows. The patient was found by passers by lying on the sidewalk, refusing to get up. The police were called and the patient was brought to hospital." (21-1-10)

Reflecting the growing diversity of Canadian society, as well as mounting public and political concerns around issues of equity and inclusion, the qualitative stories written since 2018 offer multiple references to gender, culture, language and disability. Examples include,

- "Transgender resident, born male and identifies as female, 63 years old." (19-1-13)
- "His primary language is Arabic, but he can speak some English as well. He moved to Canada about 2 years ago." (19-3-14)
- "She only speaks Portuguese." (19-3-15)
- "He identifies as part of the LGBTQ+ community." (19-4-35)
- "The patient's first language spoke Mandarin and Cantonese, but he also understood some English." (20-3-14)

- "… a 49 year old male resident who transitioned into LTC [home] from community. Diagnosis of Delusional Schizophrenia. … Note: there is an increase with younger adults being admitted to LTCH that have mental health diagnosis such as this." (20-3-16)
- "Over the past few years, more and more residents are moving into our [facilities] who speak little to no English." (20-4-01)
- "The client had down [sic] syndrome with dementia." (21-1-07)
- "The patient is deaf and communicates with interpreters, but uses a lot of slang, at one point requiring two interpreters for communication." (21-1-10)
- "A French Canadian female client, fifty eight years old, was admitted to a … district hospital … Challenges during admission included a language barrier …" (21-1-19)

Such differences have clear implications for language of care, food choices, activities, socialization and comfort level. Accordingly, stories reveal awareness of the need for culturally-sensitive care that takes such differences into account. For example, in the case of one LTC home serving residents of Indigenous ancestry:

- "BSO staff … are embracing and honouring the Ancient Tradition of First Nations People, having taken the initiative to teach one another the art and ritual of performing smudging and healing ceremonies for residents within the home. The home has a designated Smudging Room purposefully designed and reserved for purification and healing ceremonies. Staff use cedar, sage, tobacco and sweet grass to smudge within the Smudging Room; light smudging can also be performed in a resident's room should the need arise. … Because smudging is a vital form of healing for many Indigenous People, health care partners are increasingly modifying their policies and operations to accommodate smudging within their buildings." (19-4-03)

The stories also highlight the importance and challenges of providing language- and culturally-appropriate care. In the case of a LTC resident with European ancestry:

- "Many interventions were tried with [the client] with most being unsuccessful. Staff tried to engage her in activities to keep her busy, [the client] was on multiple medications (including … injections), and LTC staff even tried a volunteer visitor who spoke [her first language] … No resources were available to the home to obtain a translator to support [the client] and the staff. [The client's] behaviours escalated to the point where the staff were unable to successfully manage her care safely …" (20-2-05)

In this particular instance, language was only one of the factors at play; the individual's cognition turned out to be low, a factor initially obscured by the language barrier.

4.1.2 Dimension 2: First Contact with BSO

What We Found in 2018. In our 2018 report we observed that the BSO Framework anticipates that care will be provided to individuals wherever they are "across the continuum" to ensure "equitable and timely access to the right provider for the right services."[47]

The qualitative stories revealed that first contact with BSO can take place in the community, in hospital, or in a LTC home. They documented how BSO teams work to access and coordinate different providers and resources within specific care settings, and to support transitions between care settings when required.

What Changed? The more recent qualitative stories reveal similar patterns. The data in Table 3 show first point of contact with BSO. Given that the majority of BSO teams support LTC homes, it is not surprising that almost two thirds (64%) of the qualitative stories are located in LTC. Nevertheless, about a fifth (18%) begin in the community (e.g., family home, adult day program), while just under a tenth (7%) begin in hospitals. An additional tenth of the stories (11%) do not identify a specific point of contact; rather, they describe initiatives aimed at improving care processes and building capacity at organization and system levels through of education, training, knowledge transfer, and team-building.

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[47] 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

Table 3: Initial Point of BSO Contact in Qualitative Stories

Year & Quarter	Community	Hospital	RH/LTCH	Capacity Building[1]	Number (Percent)
2018/19 Q1	2 (8%)	3 (12%)	18 (72%)	2 (8%)	25 (100%)
2018/19 Q2	1 (4%)	0 (0%)	24 (92%)	1 (4%)	26 (100%)
2018/19 Q3	8 (23%)	1 (3%)	23 (68%)	2 (6%)	34 (100%)
2018/19 Q4	10 (29%)	3 (9%)	19 (54%)	3 (8%)	35 (100%)
2019/20 Q1	5 (19%)	2 (8%)	16 (61%)	3 (12%)	26 (100%)
2019/20 Q2	7 (22%)	3 (10%)	21 (68%)	0 (0%)	31 (100%)
2019/20 Q3	3 (12%)	0 (0%)	18 (69%)	5 (19%)	26 (100%)
2019/20 Q4	1 (5%)	1 (5%)	9 (48%)	8 (42%)	19 (100%)
2020-21 Q1	4 (18%)	4 (18%)	12 (55%)	2 (9%)	22 (100%)
2020-21 Q2	6 (24%)	2 (8%)	13 (52%)	4 (16%)	25 (100%)
Total	**47 (18%)**	**19 (7%)**	**173 (64%)**	**30 (11%)**	**269 (100%)**

[1] Includes education, training, knowledge-transfer, and other activities aimed at enhancing care delivery at organization or system levels.

In the community, many contacts with BSO begin as care needs and behaviours/expressions escalate, overwhelming care partners and providers. For example:

- “[We] received a referral … to complete a home visit … family called as she was wandering, verbally and physically responsive behaviours towards … her spouse … (i.e., hitting, biting, punching, and swearing), paranoia, refusing care, mobility issues, hearing impairment, poor memory, fluctuation in cognition, safety concerns while spouse drives, and refusing medications.” (19-3-10)
- “In July, the housing situation of a senior was introduced … Due to responsive behaviours directed at a co-resident coupled with loss of insight, police had been called; this senior was at risk of being evicted from their apartment. They were widowed and had no immediate family. … BSO staff, PRC and Alzheimer Society (AS) BSO staff member paid a home visit and met a senior who spoke clearly and insisted firmly on living independently. It was apparent that medications were being mismanaged, food intake was questionable, and risk to other tenants was high.” (19-4-04)
- “The resident had been living in the community with some supports but was very reclusive and had not been out of her apartment for over a year prior to a crisis which resulted in a hospital admission. While there was no clinical diagnosis or treatment she

was at risk, several times, of being evicted from her community apartment due to behaviours described as "paranoid" which included hoarding, covering lights and vents with tin foil, and not allowing anyone to come into her apartment. The apartment was very unsanitary when she moved out. She was non-compliant with any medical intervention while in the community and when she did enter the hospital she was in very poor shape. She was diagnosed with Dementia at that time." (19-3-24)

As this story highlights, even prior to a formal diagnosis, behaviours/expressions can pose challenges. In such cases, timely interventions drawing on a mix of providers and resources, can help care partners to sustain their caring activities, thus avoiding or delaying a hospital or LTC home admission.

- "As a support to the hospital staff and the LHIN Care Coordinator, the PRC was able to gather information from a number of community partners and suggested a care conference to explore the complex issues, including patient distress, frequent use of emergency/police services and significant caregiver burden and family stress." (19-1-06)
- "The main goal of the Care Conference was to prevent Mr. A from being discharged from adult day program because of the increased behaviours, as well as to assist the adult day program staff and caregiver (his wife) in implementing strategies to manage Mr. A's responsive behaviours at home." (19-3-14)
- "[She] is a 76 [year old] Female living in the community, with common law spouse. [She] has current diagnosis of Alzheimer type Dementia and have been receiving support from [the local] Alzheimer Society … since 2015, through the First Link Program Family and Caregivers have received support through Counselling, Support Groups (Client and Family), Respite, 3 Day Programs and Bathing. …. Due to increasing behaviours in the ADPs and changes in staffing a 2nd CSW [community support worker] referral [was] submitted ... Caregiver support over this 4 month period included 2 BSO Counselors, 2 Outreach Counselors, 2 ADPs and 2 CSWs. Caregiver also attended 3-4 different support groups." (19-4-18)

Hospitals can likewise experience difficult challenges when persons living with behaviours/expressions arrive at their door with little support. In turn, this can result in potentially avoidable admissions, extended hospital stays, and mental and physical decline, as well as escalating behaviours/expressions in an unfamiliar and challenging environment.

- "For years, emergency department (ED) clinicians recognized that the ED was not the most appropriate place to care for older adults with responsive behaviours related to dementia, addiction, mental health or neurodegenerative disorders … The ED environment contains many types of triggers and at various levels of intensity and frequency. Noise levels in the triage room and ambulance transfer hallway were often comparable to city traffic (71 dB) and in the triage room, at times, noise levels were similar to that of a vacuum cleaner (81 dB)." (19-1-03)

- "Patient is an 88 year old woman who was admitted to hospital with a probable transient ischemic attack (TIA). She also had a previous diagnosis of dementia and a mini mental state examination (MMSE) score of seven. The patient has been in hospital for several months on a transitional unit, awaiting Long-Term Care (LTC) placement. Staff referred her to BSO Nurse for responsive behaviours, including agitated behaviour (verbal angry behaviour at other patients, families and staff, physical responsive angry behaviour of throwing items on her tray, including food and personal items) and hoarding of items that are in reach." (19-4-23)
- "[a female] 85 years old, around 80lbs, who lived at home with her sister for the last 30 years … [had] entered the healthcare system and been to the ER … due to a few car accidents, elopement episodes and UTIs. She stayed in the hospital for over 30 days where it was determined she was unable to live at home anymore, related to advance dementia and failure to cope. While in hospital, she ate poorly and her blood work was low. … In the hospital, she was severely depressed, refusing all meds, sleeping all the time, and refusing the majority of her care. She would yell and swear at staff to leave her alone." (20-3-02)

LTC homes can also face tough challenges when persons living with complex needs and behaviours/expressions arrive at their door, particularly when the transition has not been well prepared.

- "Prior to admission in November 2016, she was ambulatory with a walker and required limited assistance with ADLs. She did have behaviours – demanding "wanting her purse or money now, call her parents now", focused on boyfriend (delusional about this) male co-resident. Other diagnoses were diabetes, depression, bipolar, anxiety, hypertension, asthma, arthritis, and GERD [gastroesophageal reflux disease] … From October to December 2018, resident became ill with several infections/delirium and had several admissions to the hospital. … Total assistance with ADLs, even feeding was required. She had decreased cognition, was screaming/calling at all times of the day, and had auditory and visual hallucinations. Eventually, she had a hard time swallowing, (thickened fluids and puree diet), was sliding out of wheel chair (tilt recline wheel chair used), and tried taking herself to the bathroom even with a toileting routine (her bed was lowered to the floor with fall mats)." (20-2-01)
- "The resident is an 89-year old female admitted from a retirement home in October, 2017. The resident's diagnosis includes renal failure, diabetes mellitus, coronary artery

disease, hypertension, vitamin B12 deficiency, osteoporosis, GERD, UTIs, and Alzheimer's disease. A few months ago, she began to exhibit physically aggressive behaviours towards staff during care, co-residents during meal time (primarily supper meal) and an overall change in irritability. The resident would pull PSWs hair during care or slap them across the face. She would hit/slap co-resident's during dinner time if they were "bothering" her." (20-3-14)

- "[The resident] was admitted … in April 2017 from [a retirement home]. She arrived at [the LTC home] after having lived a life struggling with bipolar disorder, fibromyalgia, an acquired brain injury and a recent diagnosis of dementia. [The resident] is 71 years old and often times shares that she feels that she is too young and does not belong here. She often refuses to participate in activities, excluding herself from the social aspect of the home. She frequently shares with team members that she does not like living here as she wishes to live independently in the community." (21-1-19)

4.1.3 Dimension 3: Care Providers and Care Partners

What We Found in 2018. Reflecting this complexity, the qualitative stories analyzed in 2018 revealed that BSO initiatives typically involved collaborations spanning different professions, occupations, organizations and sectors, within and beyond health care. Reported collaborations included community service providers, Alzheimer Societies, addictions and mental health agencies, as well as housing providers, faith organizations and police services.[48]

Confirming what a growing weight of international evidence shows,[49] the stories also documented that care partners (including family, friends and neighbours) supplied essential emotional, instrumental and personal support to individuals, as well as valuable intelligence and insight to care teams. Care partners also played key roles in transitions. Indeed, the stories suggested that when care partners were not present or when they faltered, hospital admissions and LTC placements often followed.

Of course, such efforts on the part of care partners can come at a cost. Particularly in community settings, care partners can face verbal and physical expressions of risk, 24 hours a day, seven days a week, compounded by uncertainty about how to get help when needed.

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[48] A full listing of these providers and organizations can be found in section 3.2.4 of Morton-Chang F, Williams AP. 2018. Behavioural Supports Ontario: Review of Qualitative Stories. Accessed on-line, February, 2021at https://behaviouralsupportsontario.ca/Uploads/ContentDocuments/2019-07_BSO_Review_of_Qualitative_Stories.pdf

[49] 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.

Further, the stories revealed that even when cared-for persons transitioned to another care setting, the care partner role continued. Indeed, the ability and willingness of care partners to continue to support hospitalized patients, and their willingness to receive them back into the home, were essential for effective care and discharge planning. Likewise, even following a LTC home placement, care partners frequently continued to make critical contributions through direct personal care and emotional support alongside and in partnership with providers. Stories indicated that the withdrawal of care partners could result in escalating behaviours/ expressions.

What Changed? The more recent qualitative stories confirm and extend these observations. They show that BSO initiatives typically involve inter-disciplinary, inter-organizational, and sector-spanning collaborations including care partners when present. As Health Quality Ontario (now Ontario Health Quality Division) observed, when care is fragmented, persons with multiple needs can fall "through the cracks" and end up in inappropriate care settings.[50]

The following excerpts demonstrate the scope and reach of BSO collaborations:

- "As a support to the hospital staff and the LHIN Care Coordinator, the PRC was able to gather information from a number of community partners and suggested a care conference to explore the complex issues, including patient distress, frequent use of emergency/police services and significant caregiver burden and family stress. Participants included the Family Physician, the Geriatric Nurse, Specialized Geriatric Services, Community Responsive Behaviour team, the LHIN Care Coordinator, staff from the Adult Day Program and the hospital GEM [Geriatric Emergency Medicine] nurse … PRC facilitated a meeting with the patient/spouse, the LTC [home] and the hospital staff where behaviours and potential environmental considerations were explored." (19-1-06)
- "The main goal of the Care Conference was to prevent Mr. A from being discharged from adult day program because of the increased behaviours, as well as to assist the adult day program staff and caregiver (his wife) in implementing strategies to manage Mr. A's responsive behaviours at home. The following care providers met in the Care Conference for Mr. A's case, adult day program team lead, adult day program Client Care Counsellor, adult day program Manager, LHIN Care Coordinator, BSO Support Counsellor, BSO Psychogeriatric Resource Consultant, and BSO Community Support Worker." (19-3-14)

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[50] Health Quality Ontario. Measuring Up 2019. Accessed on-line, February 2021, at https://www.hqontario.ca/System-Performance/Yearly-Reports/Measuring-Up-2019

- “At a meeting subsequent to this home visit, several community partners ([community] Housing, the LHIN, [community] Support Services) met with a relative, the POA [designated power of attorney], as well as BSO staff. Concerns were expressed of the risks with which this senior was living, however it was suggested that this senior was managing and could possibly continue to do well if some risks were addressed. It was decided not to focus on crisis long term care placement until another capacity assessment was completed by the LHIN. … BSO staff shared with the relative not only the names and contact info of the embedded BSO staff at the preferred facility, but also shared and discussed resources of how to manage a LTC move, and how to adapt to LTC. PRC, in turn, shared pertinent information with her counterpart at [the local] Behavioural Response Team. … AS BSO staff called the community OPP [Ontario Provincial Police] officer and apprised her of the situation. OPP had been called out before and noted that this senior had always responded positively to a police presence. OPP agreed to be an on-call presence at the tentative time of moving.” (19-4-04)

The stories also show that care partners figure prominently in such collaborative efforts.

- “The BSO LTC Lead Team recommendations included: collaboration of client plan of care with Physiotherapist, Restorative Department, LTC [home] Nurse Practitioner, BSO Internal Team and referrals to both the Geriatric Mental Health Outreach Team (GMHOT) and the BSO Specialized [Social] Therapist (SST). … The Specialized Social Therapist worked with staff … [and] also supported the family regarding the modification of activities the client enjoyed …” (19-1-01)
- “The NP [Nurse Practitioner] had a lengthy and frank discussion about dementia with the patient's wife. … [the] homecare coordinator took time to update the community care coordinator about patient's care needs … A referral to the First Link program at the Alzheimer's Society was initiated by our social worker. … Pharmacist spent a lot of time on the phone with various health care providers to eventually determine that patient still needed to be taking Plavix … At the family's request, a WheelTrans application was provided. This may help with transportation to ADP in future.” (19-2-17)
- “Bi monthly meetings were held with family in collaboration with internal PERT [Personal Expressions Resource Team] team, external BSO, pharmacy, MD [medical doctor], GMHOT [Geriatric Mental Health Outreach Team], pain specialist, Neighbourhood Coordinator, the Village Chaplain and Reg. dietitian. One family member was made the key contact to avoid any family dynamics, and for ease of implementing new interventions.” (21-1-01)

As noted, care partner contributions may come at a cost. As a result of their caring activities, care partners can experience burden, distress and burnout. In addition to supporting individuals living with behaviours/expressions, the stories clarify that many BSO initiatives also aim to sustain care partners so that they can maintain their own wellbeing and continue in their supportive role.

- “Over the course of our interactions with the client and caregivers the Alzheimer Society … was able to provide the caregivers, the client and outside agencies support but in this case having so many people involved including multiple teams lead to information being missed, or not shared in timely fashion, the caregiver also expressed concerns with not knowing who to reach out to or feeling overwhelmed.” (19-4-18)
- “The BSO nurse reviewed the … Nurse Practitioner’s (NP) dictation and assessment summaries from the patient’s initial Comprehensive Geriatric Assessment (CGA). The BSO nurse conducted multiple home visits and phone calls to the patient’s spouse/residence to get to know the patient and her unique situation; spent 1:1 time with family and the patient, not only to provide respite for the spouse, but to have time with the patient uninterrupted.” (20-3-19)

4.1.4 Dimension 4: Transitions

What We Found in 2018. The qualitative stories documented multiple transitions between care settings supported by BSO teams, including transitions between the family home, community-based programs (e.g., adult day programs), hospitals, seniors’ residences, and LTC homes. While typically involving movement toward higher levels of care (e.g., from the family home to a hospital or LTC home), the stories also described successful transitions back to an original care setting (e.g., from hospital to home).

Nevertheless, even when successful, the stories showed that transitions almost always pose challenges. For individuals receiving care, a transition from a familiar place could result in disorientation, anxiety, fear, loss, withdrawal, an unwillingness to accept care, as well as verbal and physical expressions of risk. For care partners, feelings of failure, guilt, shame and distress could follow the departure of a family member or friend. For care providers, the arrival of a new patient or resident living with behaviours/expressions almost always required significant time, effort and expertise to assess, plan and deliver individualized care while keeping in mind the needs and safety of other patients/residents and staff.

In many cases risks associated with transitions were mitigated by BSO teams. In other cases, BSO teams worked to avoid transitions altogether by supporting persons in place.

What Changed? The more recent qualitative stories reveal similar patterns. Excerpts highlight successful transitions *between care settings* supported by BSO teams:

- “The BSO [Acute Care Team Lead] arrived on the hospital unit to find [the person] shouting for her vase while surrounded by hospital staff asking her to sit on the stretcher. … The hospital staff expressed some hesitation around this transition, wondering if [the person] might throw the vase or attempt to exit the van while it was moving. … She chatted with staff throughout the ride to LTC; once there, she exited the van and was greeted by her husband and the BSO [Acute Care Team Lead]. The [Lead] shared [the patient's] behavioural care plan with staff at the home. … BSO teams know that transitions are vulnerable times when responsive behaviours may emerge." (19-1-09)

- "[The BSO Mobile Team] successfully supported the transition of a gentleman from hospital to LTC and then again from one LTC [home] to another LTC [home]. … Collaboration and information sharing with two [Mobile Team] primary nurses from different homes. [Mobile Team] PSWs sharing of information with other members of the LTC [home] team. … [Mobile Team] was really able to see the impact our successes can have. The new LTC [home] was eager to learn about the resident and happy to have the information ahead of time. It helped to build capacity and also eased the family member's mind knowing that we would continue to support the resident with the move." (20-2-20)
- "The patient is a 72-year old male who was admitted to the [behavioural unit]… The BSO nurse and the [behavioural unit] coordinator collaborated to ensure a smooth transfer. The BSO nurse contacted the patient's wife prior to the transfer for a warm handover. Working collaboratively with the BSO nurse in the Long Term Care (LTC) facility, the behavioural care plan accompanied the patient so follow up with the patient in LTC could occur. … The patient successfully transitioned to LTC. Since the experience, the patient's wife has become a patient experience partner and will be included in the [hospital] working group to review the restraint policy and code white procedure to make it more senior-friendly." (20-3-14)

The stories highlight the range of inter-disciplinary and inter-organizational resources marshalled and/or supported by BSO teams to facilitate successful transitions.

- "A referral was received from Home and Community Care with concern about an upcoming client transition into long-term care. A 56 year old gentleman who has been living at home with early onset dementia for several years. … It was thought that long-term care was the only options for this gentleman even though he expressed passive suicidal ideation to his wife in relation to moving into a home. In collaboration with the care coordinator, caregiver and [Mobile Team] a plan was developed in order to best support the family with the transition. … [the Mobile Team] primary nurse and PRC set up an in home assessment to connect with both client and wife prior to LTC [home] admission. There was ongoing support provided to wife by primary nurse via phone.

Primary nurse also connected with the family physician. [LTC Mobile Team] staff met with LTC [home] staff prior to admission to review the client. [LTC Mobile Team] PRC/RN and PSW support was in the home for the day of transition. Before leaving [the LTC Mobile Team] PRC/RN met with the [doctor on call] to review and make suggestions for the plan of care and discuss follow up. [LTC Mobile Team] PSW support was provided in the home for 2 days after admission and client/resident continues to be followed by our team and his wife continues to be supported. … Client/resident had a successful transition into long-term care. His wife felt supported in her decision and is now able to look after herself and her medical concerns. Resident did not have to go hospital on a Form 1 [application by a physician for a psychiatric assessment] which was thought to be probable outcome in the planning … LTC [home] staff feel supported and more prepared to do their job. Resident has been a great support at the home for other residents who have since transitioned to the floor." (19-4-26)

- "The ACBC [Acute Care Behavioural Consultant] supports the acute care sector in managing the responsive behaviours which are considered to be the barrier to discharge from hospital. The ACBC works closely with the social workers, discharge planners, care coordinators and front-line staff at the hospital to identify the triggers, manage behaviours and determine the most appropriate discharge location. ACBC collaborate with community agencies and long term care homes to help transition clients to the most appropriate care setting post their acute episode. … A comprehensive care plan was completed by the BSO Acute Care Behavioural Consultant outlining specific intervention strategies on effectively communicating with the patient. Education huddles were facilitated by the BSO Acute Care Team (Acute Care Behavioural Consultant and Behaviour Intervention Specialist) to all nursing shifts. Education was also provided on behavioural documentation and accurately documenting the patients behaviours and staff interventions. With this additional information, the BSO Acute Care Team was able to further identify gaps in learning and provided huddles on modeling support for patient care." (20-2-11)

As noted, such collaborations can also help to maintain individuals in place thus avoiding or delaying unnecessary transitions, or reversing transitions as wellbeing improves. For example:

- "LTC [home] care providers will be able to phone skilled nurses who will guide them through a decision making process to determine whether all resources have been exhausted and/or suggest care interventions before transferring the resident to the ED." (19-1-03)
- "Through our internal processes of our BSO team, antipsychotic reduction process, pain management, staff training … documentation (using DOCit), collaboration between the

interdisciplinary team and the family, [client] was able to be best cared for at [the LTC home] as we were able to utilize our strengths and ensure he was able to have quality of life. We were able to effectively prevent transfer to hospital for responsive behaviours by focusing on what the resident needed from his care partners." (19-4-07)

- "Client began calling EMS [Emergency Medical Services] weekly, but there was never anything physically wrong in the home. Client was brought to the attention of the community "situation table". Other community agencies became involved (Community Paramedics, Alzheimer Society … LHIN, Seniors Intensive Case Management) and aimed to provide support in the community. Client was assessed by a geriatric psychiatrist during this time as well, and the psychiatrist suggested an admission to a specialized geriatric unit would be ideal, but client/ family was not open to this. Client's hallucinations worsened and client went to hospital, voluntarily. … Due to the advocacy of community agencies and hospital staff, this client and his partner avoided being pushed toward LTC and will be able to stay at home longer." (21-1-03)

4.1.5 Dimension 5: BSO Initiatives

What We Found in 2018 Rather than constituting a single clinical intervention, we observed that BSO was more accurately described as a framework for a mix of initiatives aimed at improving care for persons living with behaviours/expressions and care partners. In addition to spanning different locations across the continuum of care, initiatives focused on improving care and building capacity at individual, organizations and systems levels. We also noted that multiple initiatives were often used, whether serially, or concurrently.

Individual-level initiatives included:

- Activity boxes or aprons holding interesting objects to sort through or collect
- Activation strategies and techniques such as planning activities which engage individuals meaningfully and encourage socialization and fitness
- Aquariums or aviaries to provide visual stimulation
- Behaviour reinforcement to promote desirable behaviours
- Changing the location of care (e.g., from the bed to a chair or washroom)
- Communication in the person's 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 (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)

Organization-level interventions included:

- 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.

System-level interventions included:

- 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).

What Changed? The more recent qualitative stories confirm and reinforce what we observed in 2018: BSO interventions are numerous and diverse. They take place across the care continuum. While many aim to improve care for individuals, others aim to build organization and system-level capacity.

The stories acknowledge that not all interventions are successful: some may work for some individuals but not for others in the same setting. Even those that work at one point for a particular individual will not necessarily work at others as needs and circumstances change. A willingness to engage with the person, to draw on diverse skills and knowledge, experiment with different approaches and make adjustments as needed, are recurrent characteristics of BSO initiatives.

While many of the interventions documented in 2018 were also reported in the more recent qualitative stories, the following excerpts illustrate how they continue to be used to improve outcomes at individual, organization and system levels. For example, the following excerpts document interventions aimed at improving wellbeing at the ***individual level***:

- "[The] writer sat down with resident to get to know her further. Writer explained to resident that she needs to be patient with staff since there are other residents that they are also caring for, resident understood. Writer shared with activity staff that she likes to paint her nails, hair clips, listen to radio inside her room and fashion magazines.... Writer contacted the organization and applied for the pal program which provides seniors of the LGBTQ community with weekly friendly visits in LTC." (19-1-13)

- "BSO staff brought the resident to the Smudging Room while he was having very disturbing hallucinations about snakes, guns and violence. The BSO staff performed a ceremonial smudging on the resident and witnessed an immediate relaxation and a blanket of calm come over the resident. When the BSO staff de-briefed the smudging during the next shift change, night staff reported that the resident has remained calm for the remainder of the day and through the night." (19-4-03)
- "Patient grew up on a farm, loved animals and previously owned cats. BSO RN provided the patient with a robotic cat which patient loved. Initially patient stated "this is not a real cat" and was relieved to learn it was robotic "so it would not run away." However patient eventually became concerned the cat was not eating or going to the bathroom. Patient's family started bringing in cat food. The patient was not satisfied with only dry food. Eventually, the social worker on the unit started bringing in mini cans of cat food. The staff explained to the patient that cats can only eat a tiny amount of food and the patient was satisfied with this explanation. … Outcomes included a decrease in the patient's agitation and exit seeking. The patient still packs her belongings and talks about leaving but has not come to the nursing station to call a cab and has not gone to a door since getting the cat." (20-1-12)

Other BSO initiatives aim to improve care and build capacity at the ***organizational level***. As illustrated by the following excerpts, this can be done by providing education and training, implementing standardized tools, or supporting assessments, care planning, care delivery and monitoring. Modifications to the "built environment" can make spaces more person-friendly.

- "Front line staff have implemented point-of-care charting for all residents. Electronic clinical charting at the point of care has resulted in more accurate and timely documentation of resident mood, triggers, and reasons for refusal of care. Improving the efficiency of documentation increases the time available for resident interaction." (19-2-03)
- "… multiple Residents calling for staff's attention secondary to unmet needs pertaining to loneliness and boredom. Embedded BSO LTC resource was supported in completing DementiAbility's Montessori Methods and gained enhanced knowledge of new activities to implement with residents with a focus on promoting current abilities. Activation Staff were also supported in implementing a Reading Program which has been extremely successful with residents. …Residents are more independent and able to engage in meaningful activities. Staff have been taken back by discovering the abilities of residents and their engagement in BSO programming is a lot easier. … Don't inform staff on how to do an activity, show them how successful an activity is by doing it with a resident and buy-in will be easy." (19-4-31)

- "We painted our dementia care unit in 2019. The left and right hallways on either side of the nursing station are painted in different colours. Each colour guides residents to 2 different wings. After activities or meals, residents can follow one colour to easily find their room. … Door murals were applied to high risk rooms. These prevent residents from going into the wrong room or mistaking one for an exit. … The wall murals were painted based on the daily living needs of residents. … An activity board was placed in the hallways for residents to easily use. … An aquarium mural was painted on the window glass to block the reflections. One resident saw her own reflection and mistakenly thought someone was locked on the other side of the window. She then tried to break the door open to rescue her. … A sunroom was set up for residents to relax and enjoy the sunshine. … [The home created a] snoezelen room." (20-3-08)

System-level initiatives are similarly diverse. These can entail inter-disciplinary, inter-organizational and boundary spanning connections and collaborations; local, regional or provincial education and knowledge mobilization events; and the implementation of standardized tools that support care processes and create benchmarks. For example:

- "In consultation with LTC [home] leaders, a 4.5 hour quality improvement session was planned to address the identified objectives. … Through a facilitated discussion, the team learned about the opportunities and challenges related to the on-line referral process. A quality improvement task involved small groups mapping and standardizing data gathering and submission processes as well as standardizing a data collection form to be used across the homes." (19-1-05)
- "This quarter our success has been more program specific, focusing on building our BSO inter-professional and community processes, relationships and networking, within our LHIN community and within our City … Divisional BSO groups. … We continue to expand our professional processes, which are based on evidence, best practices, and a resident centred care approach." (19-4-12)
- "[The] LHIN LTC BSO Education and Steering Committee decided to focus on Pillar 3 of the Framework: Knowledgeable Care Team and Capacity Building. This particular education was geared towards long-term care homes. The goal was to work together to enhance capacity of individuals, teams, organizations and the overall system. In order to achieve this, LTCs were encouraged to send 5 individuals from their LTC. This included the embedded BSO team members, but also Administrator's, Directors of Care, Social Workers, Recreation Therapists or whomever the LTC deemed an integral part of the BSO team within their respective LTCs." (20-3-09)

4.1.6 Dimension 6: Balancing Pharmacological and Non-Pharmacological Approaches

What We Found in 2018. In the qualitative stories prior to 2018, there were few references to the use of pharmaceuticals to manage responsive behaviours/personal expressions.

What Changed? The more recent qualitative stories demonstrate a heightened awareness of the costs and consequences of using pharmacological products to manage behaviours/expressions, as well as efforts by BSO teams to substitute, when appropriate, non-pharmacological alternatives.

The potential risks of over-reliance on drugs to manage behaviours/expressions are well documented. For example, a Health Quality Ontario (HQO) report published in 2015, titled "Looking for Balance," observed that "… antipsychotic medications may play an important role in managing the behavioural symptoms that sometimes occur with psychosis or dementia, such as agitation and aggression. However, the use of these medications has sparked controversy across the province, the country and internationally because of the possibility of harmful side effects such as sedation, higher risk of falls and slightly increased risk of death particularly for older persons living with dementia."[51]

Nevertheless, recent reports suggest that after a period of decline, pharmaceutical use is again escalating. A recent investigation concluded that "… some long-term care homes, often struggling with staffing shortages, are routinely doling out these risky drugs [antipsychotics] to calm and "restrain" wandering, agitated and sometimes aggressive patients. At more than 40 homes across the province, roughly half the residents are on the drugs. At close to 300 homes, more than a third of the residents are on the drugs."[52]

The qualitative stories echo such concerns. Although there is little suggestion that the use of antipsychotics and other drugs should be eliminated entirely, the stories recount efforts to improve their use by reviewing utilization, supporting persons to manage their medications appropriately, and substituting non-pharmacological interventions when appropriate.

The following excerpt from the qualitative stories illustrates a case in which a BSO team worked with a care partner and pharmacist to improve medication use.

- "NP spoke at length about medication non-adherence with wife, which has been a long-standing issue. Did not try to 'convince' patient to take medications - not productive.

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[51] Health Quality Ontario. 2015. Looking for Balance: Antipsychotic medication use in Ontario long-term care homes. Accessed on-line, March 2021, at https://www.hqontario.ca/System-Performance/Long-Term-Care-Home-Performance/Antipsychotic-Medication-Use

[52] Bruser D, McLean J, Bailey A. 2021. Use of antipsychotics soaring at Ontario nursing homes. Toronto Star. Accessed on-line, June 2021, at https://www.thestar.com/news/canada/2014/04/15/use_of_antipsychotics_soaring_at_ontario_nursing_homes.html

She agreed that he may benefit from a trial of blister packing. Blister packing would allow his family to better visualize whether he has taken his daily medications. It would also prevent him from mixing vials of medications (which he is currently doing). Pharmacist spent a lot of time on the phone with various health care providers to eventually determine that patient still needed to be taking Plavix. NP requested that all of his medication be dosed once daily for ease of administration. … I explained that patient is unable to manage his medications independently and needs reminders." (19-2-17)

Likewise, the following two excerpts recount instances in which BSO teams worked to implement appropriate medications regimens, the first to manage pain, and the second to support smoking cessation.

- "Staff became more aware of [the client's] pain, and worked with her two sons and the MD [medical doctor] to review her … medications to help her manage pain. With the family support, [the client's] MD prescribed a pain medication for the evening during the time that [the client] was the most responsive identified through the BSO DOS [Dementia Observation System]. Two weeks after the plan was implemented [the client's] pain decreased as measured through pain indicators. … Although BSO is non-pharmacological, the team is still able to complete pain assessments to identify clients' needs and communicate this to LTC staff." (20-2-04)
- "Research on ENDS [Electronic Nicotine Delivery Systems] was conducted and determined to be a safer option than smoking. Along with reduced nicotine content, the resident was able to be psychiatrically stable with no readmissions for smoking related behaviours in over 9 months. While ENDS is not completely without harm, this is a safer alternative compared to smoking burned tobacco." (20-2-12)

Stories describing efforts to reduce pharmaceutical use predominate suggesting both a heightened awareness of the risks of inappropriate use, and knowledge that there are viable alternatives. Three examples are given below.

- "After a facility comparison showed our facility had one of the higher antipsychotic usage rates in the province … pharmacy provided a list of residents on antipsychotics. BSO collected information like diagnoses, history of use, baseline BPSD, adherence to administration, episodes of responsive behaviours and behavioural triggers. All this information was reviewed by the MDs [medical doctors] and the process of [de]prescribing started. Antipsychotics were tapered by a 25% dose reduction weekly. … Some residents became irritable … [Other] residents were noted to be more alert. Appetite increased and gait/mobility improved." (19-1-10)

- "The medication was effective as a sleep aid, however during the day she became more confused, less mobile and her depression rating score increased from 0 to 4. She was anxious through the day, couldn't remember where she lived or where her room was. She asked repetitive questions and made repetitive verbalizations many times a day. She also had unrealistic fears and many health and non-health related concerns (cured by [non-pharmacological] behavioural interventions such as rebalancing medications, engagement in activities like laundry folding, essential oil on pillow, and better management of bed times to avoid going to bed right after supper)." (19-3-25)

- "Medications were reviewed and the recommendation we received was to wean her off the Volporic Acid (which she had been on for a long time). … Our outcome was amazing. We hoped for some improvement in quality of life and got more than we expected. Within three weeks, and during the weening off of the Volporic Acid, she was sitting up and talking. Initially she continued to do a little calling-out and trying to stand by herself. Once off the Volporic Acid, she was sitting up with assistance and playing the piano; a little stiff, but our miracle. That was in May 2019. Now, in August 2019, she is able to sit up in her wheel chair and propel herself up and down the hallway. She is walking with a walker, and one staff, up and down the hallway. She is able to feed herself and is eating a minced diet. She is off oxygen, except for exercises and walking, and has very little incontinence. Her short and long term memory have returned." (20-2-02)

4.1.7 Dimension 7: Impact

What We Found in 2018. Clinical studies typically focus on clearly-defined outcomes for the individual (e.g., the effectiveness of a COVID vaccine). By contrast, our 2018 report emphasized that the benefits of BSO initiatives accrue more widely. We catalogued a range of positive outcomes for persons living with responsive behaviours/personal expressions, as well as care partners, providers and care systems.

At the *individual-level*, stories highlighted benefits such as:

- Client less agitated, more willing to accept care, more willing to return home
- Improved sense of self-worth
- Enhanced wellbeing and quality of life
- Care partner no longer fearful, willing to continue to provide care, willing to accept individual back into the home
- Decreased risk for others.

At the *organization-level***,** reported benefits included:

- Enhanced staff feelings of comfort, knowledge, and safety
- Fewer staff sick days

- Higher work satisfaction
- Greater willingness to try new approaches
- Improved teamwork/collaboration
- Reduced staff turnover
- Staff more confident in their ability to manage complex situations.

At the *system-level*, benefits included:

- Avoided hospital admissions and LTC crisis placements
- Fewer ER visits
- Reduced hospital ALC days
- Fewer 911 emergency calls and less police involvement
- Smoother transitions between care settings
- Return to original care setting (e.g., home, retirement residence, LTC home).

What Changed? The stories since 2018 confirm that BSO initiatives produce a range of significant benefits at individual, organization and system levels. The following quotes illustrate benefits reported for ***individuals***.

- “Consistent use of interventions has decreased all of the resident’s behaviours and she does not get agitated as easily as before. … The resident is experiencing an improved quality of life. … Resident is happier. Reinforcement to staff that behaviour can be successfully managed without medication. Family members less worried and more confident that their mother is in good hands.” (19-1-16)

- “BSO provided emotional support to client’s daughter. After listening to her worries, frustration and anger re: her Mom's current situation, BSO was able to convince her to agree with sending a referral to Alzheimer Society. BSO sent referral to Alzheimer Society. … MUSIC THERAPY; GENTLE TOUCH AND MEANINGFUL CONVERSATIONS … BSO was able to demonstrate strategies of approach to daughter and grandson during visit to client. BSO also played some sample relaxation music via iPad. Both were in tears, while client was conversing with BSO. BSO held client's right hand; gently stroked the back of her hand and started to talk to her; reintroduced self and started conversing with client.” (19-3-22)

- “The combination of effective communication and medication adjustment has helped address resistance and overall improved agitation and anxiety. Her son feels closer to his mom now and better understands her disease. He is no longer wishing to bring his mother to the Emergency Department and feels supported. He is attending support groups, and is engaging his mom at home with crosswords, word searches, and colouring books as directed.” (20-2-19)

The following excerpts highlight benefits for ***organizations***.

- “Front line staff provided more person centered care and they were not as task or routine focused. They went with the rhythm of the resident. When escalating behaviours were noted they stopped and re-approached. They took the time to identify triggers.” (19-1-10)
- “Our BSO team uses so many different types of interventions, some succeed, and some don’t. We have improved some behaviours by adding in something so simple like a new fidget blanket or more one on one time; and we have improved behaviours by changing something larger like a new mattress for comfort or implementing a language board to help communicate. We have an amazing success rate with our residents because we have such an amazing support system for this program within our management, PSW’s and our registered staff. Whenever the BSO team wants to implement a new idea, everyone is always on board and hands on to help find a solution to better the lives of the residents within our home.” (20-2-23)
- “In collaboration with the management team, in-service sessions were booked to teach all staff from the front line how to properly utilize the DOS [Dementia Observation System]. It was determined that the DOS would be implemented on the home areas when 70% of the team was aware and expressed comfort in utilizing the new DOS. After two months of in-services, a review was done on how many staff remained untrained. BSO hours were adjusted to support all shifts … Better data collection, accountability of staff and accurate completion of tool. This has improved overall team collaboration and partnership.” (20-3-01)

The excerpts below highlight benefits for ***care systems***.

- “LTC [home] care providers will be able to phone skilled nurses who will guide them through a decision making process to determine whether all resources have been exhausted and/or suggest care interventions before transferring the resident to the ED.” (19-1-03)
- “Through our internal processes of our BSO team, antipsychotic reduction process, pain management, staff training … documentation (using DOCit), collaboration between the inter-disciplinary team and the family, [the client] was able to be best cared for [in the community] as we were able to utilize our strengths and ensure he was able to have quality of life. We were able to effectively prevent transfer to hospital for responsive behaviours by focusing on what the resident needed from his care partners.” (19-4-07)
- “The patient was diverted from an inappropriate destination. With the support from the BSO Acute Care Team the patient successfully transitioned from the hospital with an

appropriate plan. The BSO Behavioural Intervention Specialists supported the transition and a BSO Community Support Worker was also referred to for additional follow up. As a result the Length of Stay was reduced and advocacy for the patient was provided to maintain dignity and to recognize the patient's needs." (20-2-11)

4.1.8 Dimension 8: New Challenges in the Time of COVID-19

What We Found in 2018. The COVID-19 pandemic began in early 2020, long after our 2018 report was completed. While that report did not anticipate the pandemic, it pointed to a growing volume of more complex needs and behaviours/expressions in all care settings.

What Changed? The qualitative stories analyzed in this report cover the period up to the second quarter of 2020 when the COVID-19 pandemic was already well underway. COVID's impact was felt in all care settings, with LTC homes hardest hit. For LTC residents, the impact of existing challenges, such as staffing shortages, were compounded by isolation from other residents and restrictions on visits by care partners. The following excerpts provide insight into the difficult realities faced by residents and staff as the pandemic intensified.

- "A LTC resident referred to [BSO] for increased behaviours during lockdown/pandemic; constant requests from staff resulting in risk behaviours towards staff; insults, swearing, yelling, throwing items and hitting/kicking. Prior to lockdown/pandemic, he went out for day trips with his support worker and was a very busy individual who enjoyed making plans." (20-4-18)
- "During the Covid-19 pandemic, residents being admitted to LTC are having a great difficulty adjusting to the transfer with the limited supports allowed from family and friends." (21-1-16)

Community-dwelling persons and care partners faced similar challenges as home and community care services were curtailed.

- "Caregiver had extreme burnout due to lack of community supports due to COVID-19 restrictions. Patient was an elopement risk and becoming increasingly difficult for caregiver to support at home. Caregiver was having difficulty providing personal care, Patient was at risk of COVID-19 exposure due to wandering/elopement risk in the community and experiencing inconsistent sleep patterns." (21-1-04)
- "Client was a 49 year old [adult child] residing at home with [their] mother. The client had down [sic] syndrome with dementia. The Family Caregiver was experiencing caregiver burnout while trying to balance her [adult child's] care needs as well as her own health needs. The Family Caregiver was receiving respite care for 30 hrs. per week through an agency and hired private care for the morning. … As a result of COVID-19, the 30 hrs. per week respite services were placed on hold. Shortly after, the Private

Caregiver was unable to support due to reasons related to COVID-19. … COVID-19 has created unique challenges for caregivers who are supporting someone in the community. As in-home supports are placed on hold, Caregivers may feel isolated, helpless and exhausted. The specialized nature of BSO support (even if it is virtual) can help a caregiver feel connected, in control and supported." (21-1-07)

- "This client lived in a rural home … and became quite isolated when all programs that were supporting him and his spouse closed down when the pandemic worsened in March. The client had been attending Adult Day program two times per week and was receiving PSW supports as well in the home and when these were no longer offered the client's dementia worsened without stimulation and participation with outside care providers, so much that the client was no longer verbal at times. Our team also witnessed the burnout that was occurring in the spouse. Both the clients need and the spouse burnout prompted our team into action to find a way to provide innovative care strategies to support." (21-2-10)

Nevertheless, as suggested in the following excerpts, the pandemic also stimulated creative responses by BSO teams used to coping with difficult challenges through collaboration and teamwork.

- "Direct face-to-face interactions are discouraged (aside from high risk circumstances) in order to support social distancing efforts aimed at preventing the spread of illness. We were faced with the challenge of how to continue to provide quality care during these changing times; specifically how to provide proper cognitive assessments that are traditionally administered through paper and pen means … Our team members, and especially our patients and their family members, quickly adapted to the use of telephone and videoconference interviews/assessments." (20-4-15)
- "The biggest difficulty we face in the care of our residents with dementia is the distance we are required to maintain and the lack of physical contact. … The biggest challenge was how to continue to approach in a caring and safe way when I could not recognize myself in the mirror; adorned with masks, gowns, gloves, face shield and eyeglasses. The question to answer; if I couldn't recognize myself in PPE; how could my residents know it was me. … Then I realized, my voice had a great impact; my residents could recognize me by my voice. Whenever I approached them, I would sing a piece from a song that was familiar to them. Each resident had their own special song, and when I approached, I called them by their name using a melodic, soft and comforting tone. … Together with the help of the Recreation department, we played music and it was wonderful to see their faces bringing them hope for better days. The hope that all this will pass; and that better days will come." (21-2-11)

As the pandemic progressed, transitions between care settings became increasingly difficult. BSO teams used their specialized knowledge and ability to reach across disciplinary and organizational boundaries to ease transitions.

- "Due to the new protocols implemented to allow residents to be admitted to our home the challenge of requiring the residents to self-isolate for 14 days has taken a considerable amount of pre-admission preparation.... Assisting a resident with advanced dementia into a secure unit and following a 14 day post admission quarantine can prove difficult. [The LTC home] BSO team was able to anticipate the admission and working with the family in advance provide a variety of individualized activities of interest to the resident to assist with ease of transition through purposeful engagement. Consistency in staff also assisted to build trust and rapport and ease transition into Long Term Care despite the added challenges imposed by COVID-19 protocols." (21-1-17)
- "[During the pandemic] some changes have been made to how we are transitioning residents. In an attempt to provide continuity of care, we have implemented a transition strategy which allows our team members to visit at [regional hospital] with patients who will be admitted to our LTC home. This has provided our team with a better understanding of the patient in their current care setting. It also provides the opportunity for our staff to speak directly with the nursing staff that care for the patient and meet their family/friend/caregiver. … Lastly, we also request that the family bring personal belongings the day before admission, allowing our BSO team to personalize their space as a familiar and comforting environment and ensure they have clothes that are labelled. In these uncertain times, a little extra goes a long way." (21-2-18)

One noteworthy challenge, reported in multiple stories, was tobacco use. While never a healthy choice, smoking now became an imminent threat for virus spread.

- "The resident was a chronic smoker. He started smoking during middle age adulthood and continued smoking until the COVID-19 pandemic, when during mid-March the Ministry of Long Term Care sent Directive 3 to the LTC [homes] that residents should not to leave the property for temporary absences. … The Home decided to supply cigarettes to the twenty-five smokers residing in the Home including [this resident]. Cigarettes were provided to the smokers on a schedule based. This was to prevent the residents from gathering together and from sharing cigarettes in order to contain and prevent any spread of the virus … As time progressed the smoking times were reduced smoking from every hour down to every 2-3 hours. The home supplied cigarettes to [the resident] and the other smokers to reduce the possibility of going out and buying cigarettes." (21-2-09)

4.1.9 Dimension 9: Lessons Learned/Best Practices

What We Found in 2018. Our 2018 analysis yielded five key lessons learned/best practices, each closely aligned to the BSO Framework.

- ***Person-centred care***. Knowing the person is not a frill; it is a crucial prerequisite for the design and implementation of approaches that work for the person, organization and care system.
- ***Care partner engagement***. Care partner contributions are most visible in the community where family, friends and neighbours provide the bulk of the 24/7 care needed to maintain persons living with responsive behaviours/personal expressions as independently as possible, for as long as possible. Less commented is the fact that this role often continues in hospitals and LTC homes where care partners may provide direct personal care, emotional support, and crucial insights into the person's needs.
- ***Inter-disciplinary, inter-organizational and inter-sectoral collaboration***. Although conventional health care systems focus on episodic curative care for well-defined illnesses or medical conditions, persons living with responsive behaviours/personal expressions often present with "multi-morbidities," complex combinations of chronic health and social needs that must be managed over the long term in different settings across the care continuum. Given this complexity, inter-disciplinary, inter-organizational and inter-sectoral teamwork seem essential.
- ***Managed transitions***. Transitions between care settings almost always pose challenges for persons living with responsive behaviours/personal expressions as well as care partners, care providers, other clients and residents, organizations, and care systems. Poorly managed transitions can lead to mental and physical decline, as well as escalating behaviours/expressions.
- ***Knowledge mobilization and capacity building***. This lesson highlights the value of applying lessons learned, best practices and experiences between providers and organizations, and across sectors and regions.

What Changed? The more recent qualitative stories highlight the relevance and importance of these lessons. As population needs rise in volume and complexity, as fragmented care systems continue to struggle, and as the pandemic layers on new challenges, person-centred care, valuing care partners, building collaborations, managing transitions and mobilizing knowledge remain essential building blocks for initiatives that work at individual, organization and system levels. To this list we have added "balancing pharmacological and non-pharmacological approaches," which, as noted earlier, reflects a strong emphasis in the more recent qualitative stories on ensuring that drug use, when necessary, is appropriate and evidence-based, and where possible, is replaced by non-pharmacological interventions.

Below we refresh each of these lessons learned with results from the qualitative stories since 2018.

Person-centred care. This first lesson underscores the need to "know the person." While always crucial to validating personhood and understanding needs and responsive behaviours/personal expressions, this lesson is even more vital given growing and more complex needs, and heightened public and political awareness around issues of diversity and inclusion. Differences related to gender, language, culture, religion and disability appear more prominently in the more recent qualitative stories.

- "She only speaks Portuguese. She lived with her mother her entire life until admitted to the home. She can ambulate but requires guidance. She has a developmental delay and her cognition performance score is 3. She has short and long term memory problems. She is very attached to her mother and feels like she has been abandoned here." (19-3-15)
- "70 year old male. Single – never married. No active family members involved in his care. He identifies as part of the LGBTQ+ community. Has been living at [community support agency] since 2014 as part of the Addictions Supportive Housing (ASH) program. He has been drinking since age 20; smokes approximately 9-10 cigarettes/day. He previously resided in a Toronto men's shelter. Has a history of stroke, Myocardial Infarction (MI), Diabetes Mellitus (DM), and Parkinson's disease …" (19-4-24)

Family and care partner engagement. The importance of engaging care partners as active collaborators with their own support needs comes through loud and clear in the qualitative stories since 2018. The following excerpts illustrate this best practice in action.

- "As [daughter] describes in her letter, she was the sole caregiver for her mother … and experienced "emotional strain" in her caregiving role. [BSO lead] took the time to keep [daughter] informed of her work with [mother]. The definition of the BSO population includes clients and their caregivers, and [BSO lead's] work clearly involved all partners and embodied this definition. [BSO team lead's] work demonstrated the importance of supporting not only clients, but also their informal care partners and supports." (19-2-07)
- "A BSO package was prepared for the client's daughter which included a care plan with suggested interventions and strategies for handling different areas of behavioural concern, aggression, agitation, hallucinations, refusing care, and bathing tips. …The package was reviewed with the daughter and questions were addressed. Educational

resources were provided and a connection was made to the Alzheimer Society First Link program and Lifeline service." (19-4-25)

Inter-disciplinary and inter-sectoral collaboration. Mirroring the range and complexity of needs and responsive behaviours/personal expressions, multifaceted collaborations feature prominently in the qualitative stories as a way of bringing together diverse resources to address increasingly complex needs.

- "The BSO LTC Lead Team recommendations included: collaboration of client plan of care with Physiotherapist, Restorative Department, LTC [home] Nurse Practitioner, BSO Internal Team and referrals to both the Geriatric Mental Health Outreach Team (GMHOT) and the BSO Specialized [Social] Therapist (SST)." (19-1-25)
- "The home had made every effort to support the resident and was now asking for support if the home was going to continue to care for this resident. A resolution table meeting brought together 12 care providers including 2 hospital staff, CAMH [Centre for Addiction and Mental Health], BSOT [Behaviour Support Outreach Team], Geriatric Mental Health Outreach Team, LTC nursing, developmental services, geriatric psychiatry and geriatric addictions." (20-2-12)

Managed transitions. Moves between care settings remain a key focal point in the qualitative stories. Ideally, transitions between care settings occur only when necessitated by the person's needs, with communication and coordination between providers along the care pathway. Here, BSO teams play an essential role by working to avoid unnecessary transitions, and preparing transitions when needed by ensuring that vital information and expertise flow with the person.

- "The BSO COT (Community Outreach Team) worker provided a thorough summary of the Transitional Lead role, emphasizing that the new partner would be equipped to support [the client] on an ongoing basis, move with her through the transition to Long-Term Care, and ensure that all partners were equipped with the strategies needed to best support [the client]. The family agreed to have the Transitional Lead involved, and a joint meeting was held with staff at the Retirement Home, BSO COT, the BSO Transitional Lead, and [the client's] family to warmly share the strategies that had been effective." (19-1-08)
- "The ACBC [Acute Care Behavioural Consultant] supports the acute care sector in managing the responsive behaviours which are considered to be the barrier to discharge from hospital. The ACBC works closely with the social workers, discharge planners, care coordinators and front-line staff at the hospital to identify the triggers, manage behaviours and determine the most appropriate discharge location. ACBC collaborate

with community agencies and long term care homes to help transition clients to the most appropriate care setting post their acute episode." (20-2-11)

Knowledge mobilization and capacity building. In addition to supporting individuals, the qualitative stories document how BSO teams advance knowledge mobilization and capacity building at organization and system levels. For example, team "huddles," in-service education, and support for "trialing" care innovations, can contribute to better-equipped and confident teams within organizations. Likewise, BSO-initiated or supported meetings, colloquia and education events can enhance knowledge mobilization and capacity-building across organizations at regional and provincial levels.

- "In consultation with LTC [home] leaders, a 4.5 hour quality improvement session was planned to address the identified objectives … Through a facilitated discussion, the team learned about the opportunities and challenges related to the on-line referral process. A quality improvement task involved small groups mapping and standardizing data gathering and submission processes as well as standardizing a data collection form to be used across the homes." (19-1-05)
- "Having extra outside resources are essential in continuing to provide education and training to our staff in our LTC home. This opportunity of education gave the staff support, knowing that someone out there understood, listened to and acknowledged their situations when working with a [resident with Multiple Sclerosis] or resident who has responsive behaviours." (19-2-9)
- "… LHIN LTC BSO Education and Steering Committee decided to focus on Pillar 3 of the Framework: Knowledgeable Care Team and Capacity Building. This particular education was geared towards long-term care homes. The goal was to work together to enhance capacity of individuals, teams, organizations and the overall system. In order to achieve this, LTCs were encouraged to send 5 individuals from their LTC. This included the embedded BSO team members, but also Administrator's, Directors of Care, Social Workers, Recreation Therapists or whomever the LTC deemed an integral part of the BSO team within their respective LTCs." (20-3-09)

Balancing pharmacological and non-pharmacological approaches. This newly-added lesson learned/best practice highlights the need to continuously monitor and manage pharmaceutical use, particularly among older persons living with responsive behaviours/personal expressions, since inappropriate use can actually escalate behaviours/expressions, speed physical and mental decline, and pose deadly risks in some cases. The following excerpts illustrate this lesson:

- "A need for monitoring antipsychotic usage more closely has been recognized to increase the awareness of antipsychotic utilization and the need for monitoring resident's outcomes while taking antipsychotic medication. … The internal Behaviour Support RPN [Registered Practical Nurse] has ensured DOS's [Dementia Observation System reports] are completed after new antipsychotics are prescribed to monitor for increase or decrease in responsive behaviours targeted for antipsychotic usage. The internal Behaviour Support RPN reviews quarterlies placed on each unit by the pharmacy to ensure accuracy and the correct indication for use is noted for the antipsychotic medications. The internal Behaviour Support RPN will also leave suggestions for the doctor to either discontinue or taper an antipsychotic when indicated." (19-1-18)
- "BSO Acute Care RN upon review noted a pattern with increased physical aggression, confusion and worsening insomnia with the introduction of Haldol. … Pharmacological recommendations made to discontinue Haldol and supported by ordering practitioner having desirable effects. Daughter was also contacted to clarify shared information (between patient and writer) to help better understand patient's personhood, values and goals. Daughter was agreeable to bringing in reading material and patient's iPad to offer him meaningful activity and to reduce boredom during hospital stay. Physical aggression has stopped since above interventions have been implemented. … Improved pharmacological and non-pharmacological interventions to meet patient's needs. Reduced boredom, improved meaningful activity. Valued patient's personhood, showing importance of respectful and dignified care." (19-4-22)

4.2 Key Informant Interviews

As detailed in Section 3.2, we conducted semi-structured Key Informant interviews with 20 BSO team members and collaborators from across the province, care continuum and different professional/occupational groups.

The interviews yielded more than 12 hours of recordings and transcripts that the consultants coded independently and then cross-checked. Two overarching themes emerged:

- What happens now: demand and supply-side trends and issues
- What should happen in the future: best practices.

4.2.1 What Happens Now: Demand and Supply-Side Trends and Issues

Key Informants were asked what, if anything, had changed in the BSO landscape since 2018? Responses highlighted "demand-side" changes (e.g., those related to population needs) and "supply-side" changes (e.g., those related to service delivery).

Demand-Side: Rising and More Complex Needs

On the demand-side, Key Informants pointed to a rising volume and complexity of needs and behaviours/expressions observed in community, hospital and LTC settings.

Confirming what the qualitative stories had suggested, one Key Informant estimated that “75% of our residents [in a LTC home] actively have dementia” (KI05) and that many live with behaviours/expressions requiring individualized support. While such changes impact all care settings, they are most visible in LTC homes. According to one Key Informant,

- “Whereas it used to be a nursing home full of little old ladies who were gentle and quiet and proper, we don't see that anymore, we see fighting, kicking, screaming …” (KI12)

Another Key Informant described the needs and behaviours/expressions of one resident in their LTC home. Previously, such individuals were the exception; now they are increasingly seen as the norm.

- “So we had a lady who had frontal lobe dementia and she was wandering. Her behaviours were aggression, hitting, kicking, wandering … She would literally chase you and like go to hit you … a lot of the staff were afraid of her and they didn't really know how to work with her. So we ended up trying a bunch of different things. She had a whole bunch of other issues as well like, I think she had some past abuse and so she was scared of her washroom.” (KI09)

Moreover, these characteristics and needs are no longer seen only among older persons. Key Informants pointed to growing numbers of younger persons being admitted to LTC homes with mental illness, autism, developmental delays, physical disabilities, and addictions. While medical advances have meant that individuals with previously life-shortening or life-threatening conditions now live longer, care systems have not kept pace; most importantly, there are too few community-based care options to meet ongoing needs. Lacking such options, younger persons increasingly default to LTC. In addition to shifting the age profile within LTC homes, this adds new complexity and challenges. According to one Key Informant working in a LTC home,

- “You know, the complexity really is mind boggling. You know, there's just so many layers to peel back …” (KI04)

Other Key Informants elaborated this observation, saying:

- “I've seen a big influx in the last few years of like mental health needs … a lot younger people [with] acquired brain injuries. … So it's really changed the dynamic of the nursing home. … Trying to find meaningful activities for these younger people, when our population is so high with dementia. Right, so it's hard for these two [groups] of people to really intermingle in the facility.” (KI05)

- "It's been younger folks who ended up moving into long term care homes because there was no other place for them. And there's now a complete mismatch between where they are and what the system can provide for them so … In some ways, that is exactly what I feel is that BSO has stepped up where a lot of people haven't." (KI08)
- "… even in the six years I've seen that we have a decrease in as many dementia related cases and an increase in things such as … developmental disabilities. So a lot of people with autism, schizophrenia tendencies coming in. OCD (Obsessive Compulsive Disorder] and then you couple that with an aging population … It makes it harder to deal with …" (KI10)

Although BSO emerged historically in response to growing numbers of older persons living with dementia, Key Informants reported that BSO teams now face increasingly complex combinations of dementia, depression, acquired brain injury (ABI), spinal cord injury, autism, and substance use (e.g., alcohol, tobacco and even "hard" drugs such as crack cocaine) among persons of all ages. While one Key Informant questioned whether BSO could sustain this widening mandate, most took this as a given, focusing instead on how BSO teams could best respond.

Supply-Side: Growing Care Gaps.

On the supply-side, Key Informants painted a picture of struggling care partners, providers and care systems.

Key Informants acknowledged the crucial role of care partners in community and residential care settings: in addition to providing direct personal and emotional support on a daily basis, care partners provide essential intelligence and support to care teams. However, such support is not a given. On the one hand, more people with multiple chronic care needs live alone with no one in the household to provide support. On the other, even when care partners are present, they often struggle to access and coordinate multiple services and providers on behalf of the persons they support, as well as services like counselling and respite that they need to sustain their caring activities. In the absence of care partners, or as they become fatigued and withdraw, persons living with behaviours/expressions are more likely to default to hospitals or LTC homes even though these may not be the most appropriate care settings. According to Key Informants,

- "I think if there was adequate care at home and people could stay at home … I think that's the best thing for them, especially for someone [living with] dementia, just because change is so hard on them." (KI20)

- “There's a lot of burnout in the community, a lot of I'd say people out there that are unsupported with family members living outside the city limits or across Canada or even in the States.” (KI03)
- “I hear an awful lot because my work takes me everywhere; it takes me not just in long term care homes but into people's private homes as well, and just anywhere they might be. But I hear a lot of families struggling with maybe the time of day that the PSW's or the home care supports can get there, perhaps they're not able to make it at all one day. Or you know they're showing up at dinnertime and they're getting their bedtime medications … different little logistical things that really have a huge impact.” (KI13)

Increasingly-stretched health and social care systems add further challenges. As indicated earlier, Key Informants suggested that a lack of viable community-based care options means that persons of all ages with complex chronic needs are now being directed toward LTC homes. They noted, for instance, that supportive housing and attendant care are in short supply with long wait lists, and that community mental health resources, supposed to be strengthened after successive waves of “de-institutionalization,” remain inadequate outside of large urban centres, but even in inner cities.

- “… I think we're seeing the environment changing so where some of these people were previously cared for in a psychiatric institution or a hospital setting, I think our long term care homes are [admitting them instead]” (KI13)
- “I don't know how many years ago we've been seeing the trends in terms of increasing complexity. Number one, because people are living longer. Number two, because so many people who have different kinds of problems are ending up in the BSO bucket. So, there are many people who are not seniors who have primarily mental health problems, who end up in long term care because there is no … supportive housing …” (KI08)

As a result, LTC is becoming the default destination for younger persons living with physical and intellectual disabilities who will likely remain there the rest of their lives.

- “The example I often use is … there was an individual in [city] where I live that was 18 years old, and had no family. [The client] was in a motorcycle accident that made [them] a quadriplegic. [They] literally could be placed in long term care because [they] fit the criteria. And [they are] going to live for 70 years in a long term care facility.” (KI07)
- “Hospitals for … people living with an intellectual disability have all gone to more community models … it's really unfortunate for that person who is young and is now finding themselves in a long term care home.” (KI15)

Thus, LTC homes, and BSO teams, face unprecedented challenges.

- “A lot younger people coming into the nursing home [with] stroke, acquired brain injury that kind of stuff. So it's really changed the dynamic of the nursing home. … Trying to find meaningful activities for these younger people, when our population is so high with dementia.” (KI08)
- “And they also have their own complications, especially when you're looking at autism, where it has to be very specific things, otherwise you are looking at outbursts. Right. And the other thing that complicates this issue is that the younger individuals, they are more able-bodied. They can, you know, move a lot faster. They're a lot stronger. So if they are having a, you know, an outburst of some sort, it can, you know, not be very good.” (KI10)
- “So now to me we have frail elderly cognitively aware people living in fear in long term care based on behaviours exhibited by actively psychotic patients with a psychiatric diagnosis.” (KI07)

Paradoxically, once in a LTC home, some specialized resources such as community mental health services may be discontinued.

- “So a lot of these people have had some sort of co-morbidity that has affected them that they would require the extra care of long term care that they can't facilitate in the community. Right, so they end up here. … However, once they get in long term care a lot of the community resources aren't available …” (KI05)

Ongoing shortages of qualified workers added further complications. Even when workers are available, they may not have the skills and knowledge required to care for persons with increasingly complex needs and behaviours/expressions. Key Informants identified poor pay and working conditions as contributing factors.

- “… you see a vast difference between training of PSWs and I think that's also huge. I think if PSWs are trained and paid appropriately that would make a huge difference … I think there's not a whole lot of PSWs who want to do the work that they're doing because they don't get paid very well, they are extremely busy, and they don't do the most beautiful things. I mean they do amazing things for families, but they don't have the most glamorous job …” (KI20)

COVID-19: Layering on New Challenges. Key Informants also spoke about the impact of the pandemic. They emphasized that COVID-19 did not create the challenges they faced day-to-day; rather it worsened long-standing challenges and layered on new ones. Said one Key Informant,

- "You know the challenges that were there to begin with … the only thing I could think of at the time was this is not a drill. Like this is real, this is happening now …we are now awake to the reality of what's been going on for years." (KI18)

In the community, pandemic-related challenges took the form of shuttered community services (e.g., reduced home care, adult day programs). This forced persons requiring care to rely more extensively on care partners, when present, who in turn lost access to services like respite that they relied on to support their caring activities. Nevertheless, as care partners read front-page newspaper accounts of the pandemic's deadly toll in LTC homes, they resisted or delayed transitions to institutional LTC – and are likely to continue to do so in the future – pushing them closer to burnout.

- "People at home, with no day programs, trying to take care of their spouse with you know very little activity. … People on waiting lists now say, whoa, maybe I don't want my relative to go to long term care. And what I'm reading [on] the front page of the Toronto Star doesn't sound very good. People who enter … long term care homes from the community, from hospital, from everywhere, have to spend two weeks in isolation. And then the outbreaks in long term care homes, which have devastated." (KI08)

In LTC homes, Key Informants reported that the pandemic had resulted in wide-ranging disruptions to established routines that could worsen existing behaviours/expressions.

- "… where they're left to themselves or just alone [with] less interaction with staff, less interaction with residents, it can lead to more interaction with their hallucinations and delusions … (KI10)

This Key Informant went on to say,

- "… they've seen an increase of depression-related symptoms since the isolation protocols. … what I've seen here is the actual depression related symptoms." (KI10)

According to another Key Informant, although residents in their LTC home did not die of COVID-19, they did suffer from COVID-related "confinement syndrome" as programs and services were curtailed, familiar workers were replaced by unfamiliar agency workers, and visits by care partners and friends were restricted. (KI13) "Cohorting" residents in unfamiliar rooms without their personal belongings and communications devices (e.g., telephones), while done to limit virus transmission, were also identified as factors increasing the likelihood of decline and death.

For new admissions to LTC homes, the challenges were just as formidable. They faced 14 days of isolation, in unfamiliar places, without their own furniture and belongings, and sometimes with no direct contact with families and care partners since telecommunications installers (e.g., telephone, cable) would not enter LTC homes.

- "They leave the family, and so on this terrible heartbroken time you know they don't want to come to a new place … all the people are strangers. There's even no family around … it's hard for them to stay in the room, they're just very anxious and walking around looking … terrible." (KI15)
- "It's even worse now. It's like basically they're dropping their loved one at the door and that person is going into a barren room in a lot of cases, and I speak that from experience. They go into a barren room and are expected to be there for two weeks. With no support, with no one there, with no family. So as an individual that has some cognitive impairments, when your loved one drops you off at the door and you don't see them for two weeks, how do you feel? You feel abandoned." (KI07)

For overburdened staff "already scared to death" by COVID (KI09), new admissions could be daunting, since people would literally "show up at the door" without an "I am who I am assessment," or any meaningful insight into the person's likes, dislikes, preferences, hobbies or cultural/religious beliefs. Moreover, available staff had no time to "sort through" or "figure out" why a behaviour/expression was happening before new residents were isolated in their rooms. (KI01)

Such circumstances directly impacted BSO teams, who were frequently called to put aside their specialist activities to provide basic care and support to residents. For instance, BSO transitional teams, normally tasked to prepare transitions into LTC, now modified their work to focus on the "highest need" homes. For homes in outbreak, it was a case of doing anything needed.

- "We were no longer really doing BSO work. We were just all hands on deck so we were helping with screening, we were helping on the floor … they were helping in any way they could." (KI01)
- "… if we're talking about BSO staff, a lot of those staff are being pulled and working in other capacities." (KI04)
- "We've seen where if it's very easy for people to be pulled into things and pulled out of the role that they're going to be playing if they are embedded because all of a sudden it's like well you're not this specialized person … you're going to be pulled into this wing or that wing …" (KI18)

Under lockdown, long-standing challenges like tobacco use took on a new urgency. Smoking now had to be curtailed so that smokers would not congregate, leave the premises to buy cigarettes, remove masks, share cigarettes or lighters, or touch their fingers to their lips and then to door handles and elevator buttons. BSO teams worked to manage this now potentially deadly behaviour.

- “So we only have a few smokers left. It was a huge change, especially in rural Ontario … our last three smokers will not be able to go outside. … we have that smoking cessation program available immediately to decrease the risk of these responsive behaviours.” (KI06)

Similarly, wandering/exploring, or walking from place to place, normally considered behaviours/expressions with low risk, now became deadly threats for COVID-19 transmission. Drawing on their specialized expertise, BSO teams worked to find solutions.

- “The other thing was wandering … when you look at responsive behaviours, wandering is probably the one that you worry about the least, but then when we went into an outbreak situation, the risk to residents, not only to themselves and to others increased exponentially. … the wandering care pathway that came out from BSO and I believe it was the brainXchange, kind of came out right at the beginning of outbreak and I wish we had more planning …” (KI05)

Ironically, Key Informants reported that in some instances behaviours/expressions actually declined in LTC homes. They attributed this to less traffic in hallways, less noise, and fewer congregate situations where residents could trigger each other.

- “They settled out because again, when there's visitors, when there's parties, when there's commotion … [it’s] unsettling to a lot of people … there's more hubbub, there's more noise, there's more stimulation. Well, now it was just the people that they worked with every day and there wasn't the comings and goings … after the initial probably couple of months people settled into their new normal.” (KI07)

Similarly, as residents in older homes with four-to-a-room wards died or were transferred elsewhere, behaviours/expressions declined.

- “We started with XX residents at the beginning of this pandemic and now we're eventually going down to XX [about two thirds of the original number] because the rooms had four in a room because it's such an old home …” (KI12)

However, it is important to clarify that Key Informants did not suggest that confining people to their rooms was a desirable thing to do: lockdowns and isolation resulted in many negative outcomes for surviving residents, care partners and staff. Rather, the lesson learned is that environments with less noise and more privacy are better for residents, particularly those living with behaviours/expressions.

4.2.2 What Should Happen: Six Best Practices

As well as identifying demand and supply-side challenges, Key Informants offered lessons learned/best practices for the future. Six best practices emerged.

Deliver Person-Centred Care

This first best practice requires care built around the needs, experiences, preferences, beliefs, likes and dislikes of the person. Rather than being treated as impersonal "cases," person-centred care emphasizes "knowing the person" and treating each individual, including care partners, as active participants and collaborators. Key Informants insisted that person-centred care is, and should remain the foundation of BSO work. According to a Key Informant,

- "I want more for these patients. I want them to be heard…. I want them to be honored for the people who they are ... Whole person assessment: gather all information; identify possible triggers; drilling down to find out why a behaviour is happening. "Are we noticing pain?" Trial a bunch of initiatives and find out what works best for the person. Try it and show staff the results. Model the approach. Coach staff. Check results. Involve family." (KI03)

Key Informants also emphasized that "person-centred care" must be more than just a catchphrase. This means taking the time to learn about the person, to understand their needs and to find out what works for them, even if not every attempt succeeds.

- "No two residents are alike … it's not just about basic needs anymore. I mean, it's about figuring stuff out. It's about making their lives worthwhile and I mean it's about making their environment safe." (KI04)
- "I would like to think I serve as a detective where I will just watch; I'll do an observation for a couple of days. I'll watch every interaction and everything that the person is going through, what they may be experiencing, before I necessarily interact with them or with the staff. Because a lot of the time … unmet need is what is causing the behaviour. And it could be something as simple as them needing to have more frequent bathroom visits or it could be something a lot more complicated that requires continuous investigation …" (KI09)
- "Building the relationships and building trust and creating a quiet predictable environment. So we are able to sit with them and talk to them, and when we're giving a shower we have to take our time and discuss past relationships and past history …" (KI12)

Key Informants contrasted person-centred care with a "task-oriented" approach. Rather than "knowing the person," too-often the focus is on getting things done whether or not these align with individual needs and preferences.

- "Often times staff in these homes are working on multiple units and they're part-time because they don't get paid enough so they're not working consistently with these people." (KI09)

- “Most PSW's are very task oriented, they need to get their work done and get through the day, so we need to change their mindset about what it means to be a caregiver. It's not necessarily getting the shower done, getting the food into them and changing their briefs. It's more about relationship building and trust building …” (KI12)

In contrast, finding out what works best for the person takes time and effort. Standardized tools and approaches familiar to BSO teams can assist.

- “We're using the psychosocial approach of the PIECES [Physical, Intellectual, Emotional, Capabilities, Environment, Social] model where we're investigating the person's physical needs, their intellectual needs, their environment, their capabilities, their emotional needs, and their social needs.” [53]

Looking beyond the individual, Key Informants said that BSO teams, whether embedded in specific care settings or working across different settings, played an important role in improving practice.

- “We certainly need to transform not only where we provide the care, but how we provide the care. And it's really getting people on board with some of the simple things of treating people with dementia, like they’re people. Nobody's doing it intentionally with any ill will there. I get it that frontline staff are so strapped and so stressed and so pulled that they go with what they know, which is task focused. It's that survival mode.” (KI13)

While recognizing that there was always more that can be done, BSO efforts to promote person-centred care received strong affirmation. The following quotes are typical:

- “Can’t get a more valuable program than this” (KI04)
- “[BSO is] so important, so important. I'm so grateful that we got the funding to have the program, actually just very grateful that we have this resource even available. We've come a long way in the last year.” (KI05)

Bolster Inter-Disciplinary, Inter-Organizational Collaborations Including Care Partners

Key informants emphasized that particularly in fragmented care systems, inter-disciplinary, inter-organizational collaborations that include care partners can go a long way to ensuring that people with complex health and social needs and responsive behaviours/personal expressions receive person-centred care in the most appropriate care setting.

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[53] Baycrest. (No date). P.I.E.C.E.S. Accessed on-line, March 2021 at https://www.baycrest.org/Baycrest/Education-Training/Educational-Resources/Responsive-Behaviours/P-I-E-C-E-S

However, Key Informants worried that in spite of decades of exhortation about the need for collaboration and teamwork, and waves of system reforms aimed at integrating care, care systems remain fragmented and uncoordinated. Said one Key Informant, in spite of “a lot of talk about collaboration between organizations and sectors, collaboration was still ‘a work in progress’.”

In this connection, Key Informants observed that BSO team members worked hard to facilitate collaboration and teamwork. For example, BSO team members in LTC homes described their efforts to coordinate with PSWs (personal support workers), nurses, PTs (physiotherapists), OTs (occupational therapists), nutritionists, physicians, other workers and care partners to provide the best possible care for residents.

- “We definitely took a very collaborative approach. So, you know, you would have the BSO staff there with the psychiatrist. Family was always involved … maybe it was not necessarily the PSWs that knew the resident best. I mean, people from environmental or kitchen staff or really anybody that knew that person well was invited to attend.” (KI04)
- “… huddle talks with the staff … I always go around and find out how everybody's feeling about everything. We frequently use the DOS [Dementia Observation System] tool. … let's start the DOS tool for five to seven days and try to capture some of these patterns. See if there's, if something's going on … those are our little times to connect with multiple staff … just to let them know that it doesn't take a doctor's order. If you are struggling with a patient and you want some advice, call me, call my extension, email me.” (KI03)

In addition to mobilizing in-house resources, Key Informants said they would reach out when appropriate to specialists such as geriatric psychiatrists, pain specialists, and neurologists. Said one Key Informant,

- “[LTC] is great for one stop shopping. But I think if we're talking about just the complex support needs that these people require … sometimes you don't have access to a neurologist’s doors. Some of those specialist services sometimes get dropped … I mean, I think, not everybody had geriatric psychiatry either …” (KI04)

In another example, a BSO lead had reached out to a local health unit to implement a smoking cessation program.

- “We've had a significant amount of issues with smoking in our home … We had the public health unit come in to facilitate a smoking cessation program … this was the best thing that we have ever done … these seven people no longer smoke.” (KI05)

One Key Informant noted that such collaboration can also avoid overlapping or duplicative initiatives by raising awareness of what others are doing. Said one Key Informant,

- “Who's working with whom? I think we need to collaborate better … if it’s going to be a cross-cutting strategy then it needs to be partnering better with those other strategies because people still seem to be going on parallel tracks for the most part, caregiver organizations included. And yeah there's lots of parallel work and we were trying very hard to keep track of it all and to pull it all together. But it becomes hard to be a connector all the time because there's so much going on. It's good work, but a lot of it's parallel.” (KI08)

A helpful approach used in one region was to create a “table” where diverse resources could be marshalled and coordinated.

- “In [this region] for instance, we have an initiative for many years now called the complex case resolution table for individual cases in long term care homes that are really challenging. So the local resources on the ground, the behavioural lead, the geriatric mental health outreach team, the PRC, the long term care behaviours support it. … when everybody's sat around, done their best, really thrown everything they had at it and they're still wondering what to do, then they might go to the BSO office and say, we'd like to have a complex case resolution table.” (KI08)

Support Transitions

Key Informants talked at length about the importance of ensuring that transitions between care settings are well prepared in advance particularly for persons living with complex needs and behaviours/expressions who may require support to adapt to new places and faces. They emphasized the need to “follow the person through the system” and to make sure that crucial background information and assessments arrives *before* the person. Well planned transitions can also avoid situations in which families and care partners burn out precipitating emergency hospital admissions or crisis LTC home placements.

- “… the hardest thing in our system is to work on transitions. Because sometimes, the Community has come to the end of the road and they've done their best, and they cannot do anymore. … I mean, no matter how much care we provide … how much respite, and how much modeling we do … some families have just done their work, and done it and they cannot do any more.” (KI08)

Nevertheless, many times persons with complex needs and behaviours/expressions still “land up at your door” (KI05) without adequate preparation. Staff in the receiving care setting then have to start from scratch, doing their best to learn about the person even as they cope with their immediate needs. Besides causing stress and anxiety for persons and care partners, this forces staff to struggle to make sure “the wheels don’t fall off.” (KI04)

Well-prepared transitions are increasingly vital as needs and behaviours/expressions become more complex. Without planning what comes next, persons may end up “stuck” in inappropriate care settings such as acute care beds when they do not require acute care, impacting negatively on their physical and mental wellbeing while further stretching already-stretched hospital resources. Said one Key Informant working in a hospital,

- “…they're dealing with acute mental health patients and then patients with dementia … these patients that come through those doors, they're labeled, stigmatized and then we can't place them.” (KI03)

This same Key Informant went on to say that, in spite of such challenges, progress was being made, often as a result of BSO efforts to establish and maintain lines of communication across organizational “siloes.”

- “Yeah [coordination happens] regularly when my patients are getting ready to be discharged to long term care … Well, I'm having those conversations with the BSO long term care team. We would have monthly meetings … just to keep that relationship going, talking about what's going on out there.” (KI03)

In this connection, BSO teams have the considerable advantage of being able to reach out to their counterparts in different care settings to prepare transitions. While the excerpt below pertains to hospital-LTC home transitions, BSO teams also facilitate transitions in both directions between community, hospital and LTC settings.

- “… if we can get these teams going within hospitals and community and all the areas that I spoke of … we can be the familiar support to the family and to that individual when they come to long term care. There's a familiar face.” (KI07)

In addition to ensuring smoother transitions in specific cases, such efforts can establish durable pathways that do not have to be re-created for each and every transition. One Key Informant pointed to efforts made by BSO teams to strengthen inter-organizational connections and build system capacity.

- “… we're also working on, like a transitional support resource model that is going to be accessible by … a busy clinician or a PSW or a family member... So we're getting to know each other right now, which is huge because before I think there was always that sort of disconnect.” (KI09)

In turn, shared resources can stimulate a positive cycle of stronger communication and collaboration.

- “Well there's always been transitions but for some reason, I guess, there was a gap that was identified where we could have more support and more help and we've just really ramped up and seen a lot of success … information sharing, I think, is the biggest thing and where we can most be helpful, especially when people are going to long term care homes … if we can do some nice transition care planning, that's really helpful.” (KI13)

Advance Knowledge Mobilization and Capacity Building

As reflected in the quote above, Key Informants emphasized the critical role of information sharing and knowledge mobilization, not only to address immediate needs, but to build capacity at organization and system levels.

Key Informants said that they facilitate team meetings in their organizations where staff share experiences, hear ideas from peers, gain insights from care partners, and access specialist knowledge.

- “There's the opportunity to ask questions. You know, the staff can maybe bring up something like ‘why would you be using this medication as opposed to this medication’ or ‘can you explain, you know, that Lewy Body dementia piece a little bit more’. ‘Why are we seeing this with this particular diagnosis?’ It just opens things up so that we have that base relationship with the psychiatrists and the staff and the families. And so it's just a really good capacity building opportunity …” (KI04)
- “We are always building on that stockpile of information and encouraging them and saying you know, ‘were you able to share that with your team, were you able to share that with your lead, with the nurse manager?’ … Because we want them to know that their input, their experience, their successes, are equally as important and inform our practice moving forward. So I can honestly say that we've also seen teams … where they get equally as excited when something is successful, or when they've been able to contribute to a really positive outcome.” (KI19)

Another Key Informant noted that established lines of communication are particularly important during periods of extraordinary stress such as the pandemic. However, this is also when staff are least likely to be able to take time away from pressing everyday tasks or add unpaid time to already long days. One suggestion was to add a small amount of paid time at the beginning or end of work schedules so that staff could engage collectively, share experiences, and see that their contributions are valued.

- “… for sure, medical issues first. If you have a UTI (urinary tract infection) … [you have to] rule this out. And then … figure out what's the root reason, the possible triggers … [then develop] a care strategy … share with the frontline staff, and then they will be coached on how to do that. … if we can pay for 20 minutes after their work, I believe they [staff] would like to stay and like to talk. That's very important not just teach them, you know, sometimes they teach me … they have a lot of experience ...” (KI15)

Key Informants also highlighted approaches used to advance knowledge mobilization and capacity building at a system level. One Key Informant spoke to the progress that had been made in one region by bringing people and knowledge together.

- “For me, we definitely have made incremental improvements and changes that are positive… I feel like there is a system there. Now, with respect to different partners it can still be improved and we're still tweaking it and working on things … But I think … especially in the last five years, there's been a real kind of solidification of what we have.” (KI08)

Another Key Informant spoke of the resources being marshalled by BSO teams at the regional level to build capacity.

- “… we have a psychogeriatric resource consultant who can provide education … Montessori DemetiAbility, Gentle Persuasion …PIECES training. … we also have within the last year an Occupational Therapist that has been hired that works with our team as well. So we are able to build capacity.” (KI07)

Key Informants also highlighted the value of educating staff about the use of standardized tools. The BSO Provincial Coordinating Office (PCO) was singled out as a particularly valuable resource for identifying issues, disseminating information and promoting the use of standardized tools across the province. (KI04) Similarly, the brainXchange received accolades – “wonderful” (KI05) – for its ability to mobilize knowledge.

- “They do have a website called brainXchange which is very informative. They have a lot of events that are mainly free … the last couple … have been around pharmacology … sexual relationships between residents has been another one … how do you handle these scenarios and make sure everybody's safe …?” (KI10)

As noted earlier, Key Informants observed that during the pandemic, BSO team members had been pulled away from such activities to deal with urgent care tasks. In the post-COVID period, however, it would be essential to resume and expand these activities, particularly since, as a result of the pandemic, there were now many new residents, workers and senior administrators in LTC homes and other care settings. (KI04)

Balance Pharmacological and Non-Pharmacological Approaches

As noted, the Key Informant interviews highlighted the importance of moving away from what many judged to be an over-reliance on drugs for managing behaviours/ expressions, to non-pharmacological approaches aimed at understanding the person and addressing unmet needs through non-drug interventions. Said one Key Informant,

- “I know that there's other ways that are non-pharmacological to work with people who have dementia, absolutely. And they were over-medicated but now we're more easily recognizing that the little old sweet lady might actually have a diagnosis of anxiety. A true diagnosis of anxiety … so it's not necessarily the dementia that's causing her distress, it could be dementia with anxiety and or depression …” (KI12)

No Key Informant advocated eliminating the use of drugs to manage behaviours/expressions. Nevertheless, they were clear that drugs should not be used as the first resort and only where the evidence indicated they were appropriate.

- “We don't want people trying medications they've already had … there might be things in their history that explain why they're feeling or acting a certain way now, so I feel like a real detective sometimes, but it's important.” (KI14)

Key Informants provided numerous examples in which they had worked to find activities or resources such as music or art that were meaningful to the person, rather than relying on drugs. This created a kind of a “virtuous” cycle in which drug use was further reduced as behaviours/expressions moderated.

- “For instance, we had one lady with an acquired brain injury, she would have really manic periods … And she's very young for our population and she didn't have a meaningful activity. She didn't find meaning in bingo, or the [robot] cat …. she couldn't remember anything past like three minutes. … She constantly would get upset and anxious and it was a cycle. So we actually made her an activity assistant within the home.”

Key Informants reported cases in which they judged that the drugs given to individuals were not appropriate or effective; instead of meeting the needs of the person, they were driven by worker shortages or a lack of time to develop and deliver person-centred care plans. However, even when front-line staff such as PSWs believed that drugs were not working, or were counter-productive, they might not feel able to question the prescribing physician. In such cases, BSO team members could play a helpful role.

- “… we can observe timing, like, oh, the person got their medication, yes or no, or at the wrong time, or I think it was effective or ineffective. But we, I can't go to a doctor and be like, hey, I don't think this person should be on, you know, Prozac right now. But the nurse might be able to say, you know, we investigated this person's past and [another approach] may be more appropriate …” (KI09)

Such stories also highlight the value of devising interventions that not only address individual needs, but engage and educate entire care teams about the care of residents.

- “I'm developing a psychotropic de-prescribing program with the physicians … It's where they're trying to safely de-prescribe these psychotropics … The goal would be really to have everyone off of psychotropics [although] it's not always possible …” (KI05)

Use Technology as an Enabler

If the pandemic had produced any benefits at all, Key Informants observed that it was in the form of a greater appreciation of the role that technology can play in connecting people to people and people to care.

Key Informants reported that during the course of the pandemic, and particularly during lockdowns when in-person meetings were not possible, technology allowed essential BSO work to continue. This included virtual consultations with specialists, who even in pre-COVID times were difficult to meet with in-person. Said one Key Informant,

- “It's always better in person. But I think that's been a huge barrier in terms of cost and people working night shift, different shifts. So if there's things that can be recorded and people can review them, I think that's amazing. The other thing too is we have a lot of consulting specialists that aren't necessarily in proximity nearby… this technology is very, very helpful in that regard. I mean I hate to see it become so much a best practice that we lose the in-person connection …” (KI14)

Likewise, an inability to conduct in-person assessments had spurred innovative approaches to doing them virtually using iPads, computers and smart phones. In turn, this had forged new connections between BSO team members and collaborators, both near and far.

- “I've had a lot of success … not necessarily using Zoom but using OTN [Ontario Telemedicine Network] to do these consultations and do some cognitive testing virtually as well. So there was an excellent webinar that I attended at the beginning of the pandemic that talked about ways to modify your ability to do cognitive testing virtually. And we've really shared that information fairly widely and have had some success with making really good connections with people, which I was surprised to virtually to be able to gain that rapport. But it worked really well …” (KI14)

Education and knowledge mobilization had also advanced as technology enabled new linkages between team members in different locations. Just as importantly, more thought was now being put into not simply making connections, but thinking of new ways in which resources and ideas could be used to bring “knowledge to practice.”

- "… creating virtual education and not just doing the "same old, same old" but on Zoom or [Microsoft] Teams. Really changing the delivery, really pushing the providers of the core curriculum be it GPA [Gentle Persuasive Approaches] or DementiAbility to create virtual delivery models that really helped or enable knowledge to practice or really helped the adult learner. It wasn't, we call it zoom fatigue, of sitting and listening to something that's supposed to be in person … we need them to be emotionally present as well or it's going to go in one ear and out the other." (KI13)

One Key Informant observed that while many meetings could be conducted independently, regular meetings with the BSO regional office had been particularly helpful in bringing larger groups together and sharing information and lessons learned.

- "Plus the BSO office and the PRC had been holding a weekly check-in with the behaviour leads for the … homes and the [region] … which I think has been a very helpful morale booster and wellness booster in addition to a problem-solving booster." (KI08)

Particularly during lockdowns, when in-person visits by family and friends were curtailed, technology had also shown its potential to keep people connected.

- "Yeah, so sometimes you need to help her on the other end of the camera, a family member… but yeah we've had great success with just changing the way we're delivering the instructions … to be able to set them up with their pen and paper … they're able to hold up their written portion to the camera and we can take screenshots and whatnot so that's been really nice." (KI14)

Further, iPads were now being used to access music, art and entertainment, in order to reduce isolation and keep people engaged.

- "We had given this client this iPad and it was amazing because we programmed it so that I had music and therefore when she was hyper-aroused … I had sermons in the morning because … that was her routine in her life, you've got up and gone to church or she had listened to church sermons in the morning …" (KI09)

Of course, Key Informants recognized that in spite of such advantages, not every household or person had access to needed technology, or the ability to use it. Particularly when in-person visits were not possible, this could produce inequities that needed to be addressed.

- "… they don't have Internet, they don't have a computer … and if you have a family member who did they're trying to balance all the other things in life and dealing with the pandemic, so they don't necessarily have the time …I think there's a lot of work that can still be done in that sense, and just making care accessible, even from home because I know for a lot of seniors getting people to Adult Day Program is hard, or getting people to appointments is hard, so I found a lot of people actually really enjoyed doing virtual doctor's appointments, but on the other side, some people didn't like those because the doctor didn't see the client either so there's kind of both sides." (KI20)

4.2.3 For Continuing Discussion: Embedded and Mobile Teams

A recurrent issue, raised by a number of Key Informants, concerned the relative merits of embedded BSO leads and mobile BSO teams.

On the one hand, Key Informants observed that embedded leads have the strong advantage of being able to build trust with staff, residents and families and establish strong, durable relationships. They also had more scope to educate and support staff, try out different approaches, demonstrate effectiveness, and put them into practice. On the downside, BSO embedded leads reported that they were sometimes pulled away from their BSO work to do routine tasks caused by escalating needs and worker shortages.

On the other hand, mobile teams were seen to have the advantage of a broader system view along with access to a wider range of specialist resources (e.g., neurologists) not generally available within a particular organization. A disadvantage is that these teams have less opportunity to engage with staff in a particular setting, to build trust, trial approaches, and encourage the adoption of best practices learned elsewhere.

However, no Key Informants argued that it should be one or the other. In fact, virtually all suggested that embedded leads and mobile teams offer complementary strengths increasingly needed to respond to growing and more complex needs in all care settings. According to one Key Informant working in a LTC home:

- "I think it's a little bit of both. Honestly, because the mobile response team is still available to me. So we brainstorm within the home …we've had a lot of education. We try to do our PIECES, work out like physical, environmental, what's going on around them that's causing these issues. So when we're at a loss …it is most definitely appropriate to have those backups. … We have monthly meetings actually with them and we have our standard group that we review and they are just so important. … Instead of trying to reinvent the wheel we'll trade back and forth." (KI05)

A member of a BSO mobile team offered a similar perspective, suggesting that there was a working division of labour in which mobile teams and embedded leads each brought crucial skills and knowledge to the table.

- "I go into the [LTC] home periodically, but [the embedded BSO] PSW would be assigned to be there daily to sort of do the hands on, eyes on, day-to-day things alongside the staff. Develop interventions along the way and some strategies in which to help manage the responsive behaviours; that is my role … Now we've developed collaborative care plans based on the strategies that have been developed by our team and the home." (KI07)

Said other Key Informants,

- "So, to avoid that duplication and really help the homes out, we said, you know what, you refer directly to the mobile team, and then the mobile team comes in, they do their observation. Once they've completed the observation, the PRC is going to meet with the mobile team RPN and PSWs and collaborate." (KI13)
- "When the mobile team started, [the question was] how do we avoid duplication? …so we did some work with that. The team started up and we're really quite proud of a collaborative model that we, I'll be honest, we kind of recommended it from the beginning." (KI13)

Collaboration between mobile and embedded teams was universally supported by Key Informants because of its capacity to "raise the bar" on care for persons living with behaviours/expressions and build much needed capacity at organization and system levels. Said a Key Informant working on a mobile team,

- "Right, so it was a … blended or a hybrid model, where there were internal resources and then our mobile response team…. I really appreciate how the embedded will be able to flag things earlier … However, I [also] appreciate how the mobile team has that very focused and specialized knowledge. What we learned through that was it's not just about custodial care it's about developing very detailed behavioural support care plans … I think that speaks to … the vision for us having the blended model … the long term care homes with internal support, as well as our external supports coming in." (KI16)

In addition to supporting LTC homes, mobile teams worked in community and hospital settings, thus adding a valuable system-wide perspective.

- "[This] region has … psychogeriatric resource consultants [PRCs] … supporting … long term care homes and community agencies, including day programs, and so that initiative has been around since the inception of the provincial program as part of the Alzheimer strategy. So we do knowledge-to-practice work related to supporting frontline staff with capacity building around responsive behaviours related to dementia, mental health problems or other neurological conditions. … We develop topic specific customized education, building on best practice and evidence." (KI13)

This Key Informant went further, observing how mobile teams in their region were working with, and learning from, teams in other regions, to broaden the knowledge base and build capacity on a regional and provincial basis.

- "A lot of the homes really advocated for themselves and wanted an embedded model, so we have a bit of a hybrid model going on here … We work very closely with our PRC colleagues to the north … [and] to the south …" (KI13)

4.3 Lived Experience Forum and Interviews

This section of evaluation findings adds a crucial perspective: it documents the "lived experience" of persons living with dementia and care partners, those at the centre of BSO work.

As detailed in Section 3.3 above, we used two complementary approaches to record lived experience: an on-line forum, and semi-structured interviews with individuals who did not attend the forum. Together, these approaches generated more than four hours of recordings and transcripts.

Since there was considerable overlap in findings from the forum and interviews, we have combined them below.

Two over-arching themes emerged: the first speaks to the challenges faced by individuals and care partners when attempting to access person-centred care; and the second, best practices to improve access to, and the quality of care.

4.3.1 What Happens Now: Accessing Person-centred Care

Forum and interview Respondents strongly validated the idea of "person-centred" care, that is, care tailored to the experiences and preferences of the person, as well as their clinical needs. This means not only knowing the person and care partner at the beginning of the care journey, but continuously adjusting and adapting care as needs and circumstances change along the way.

However, from the perspectives of Lived Experience forum and interview Respondents, person-centred care can be notoriously difficult to access; a variety of challenges can stand in the way.

Having Voices Heard

A first challenge, said Lived Experience Respondents, is getting providers to listen. Forum and interview Respondents observed that for a variety of reasons related to the nature of professional education and roles, heavy workloads, and a simple reluctance to hear those who are not trained professionals, persons living with dementia and care partners can find themselves trying, without success, to have their voices heard. Said one forum participant of their attempts to convince a health care professional that they were experiencing early-onset dementia (later confirmed),

- "You know, with me, it was a joke, I was called a hypochondriac." (LEF02)

Others reported similar experiences.

- "I felt I wasn't getting anywhere with the doctors. Okay, so I kept pushing and pushing and pushing and pushing because I really felt I wasn't getting anywhere … I felt like I wasn't being taken seriously … [they] just thought I was faking. (LEI03)

This person went on to say that getting an accurate diagnosis had taken persistence. Not just one provider, but a whole lineup of different providers all had to be convinced.

- "… at that time I was seeing three neurologists and really was not getting anywhere. When I wasn't getting anywhere with the neurologists and I knew something was wrong, I actually went to the Alzheimer Society and kind of asked for help. They gave a cognitive test and it seemed … to get the ball rolling … even my family doctor two weeks before my diagnosis says no, you don't have dementia, until we got the letter from the neurologist that changed his mind." (LEI03)

Recounting a similar experience early in their care journey when a diagnosis by a physician seemed to be incorrect (later confirmed), a forum participant said,

- "We were clashing with different doctors and we were clashing over the particular course that they wanted to take and we didn't agree with it. And so we ended up with one particular doctor basically firing [them] … and so we've had a really rough go of it … so we just started asking to see our records all the time, so we knew exactly what was being said." (LEF07)

Another forum participant spoke about the challenges they faced when trying to get staff to listen after her husband was admitted to a LTC home.

- "I found early on, after my husband was transferred there that if I didn't make a point of speaking out nobody would. … I just went right to the director of the building. And generally my voice was heard, but my fear is, for many people … in that seniors category, that unfortunately, this group just kind of accepts what the professionals tell them because that's what they've done all their life." (LEF04)

Lack of Recognition and Support for Care Partners

After diagnosis, persons living with dementia and care partners were too-often left on their own to navigate their way through different providers, programs and services that all worked independently with their own rules and requirements. In doing this, care partners said they were often ignored or discounted.

- “Family members and friends, as you know, [are an] essential part of the care team. This importance cannot be underestimated, [but] it is.” (LEF05)

In addition to providing day-to-day support to persons living with dementia, care partners said they also had to learn new roles as advocates and care coordinators with little education or support. According to a care partner assisting a parent living with dementia,

- “I think, from someone coming from the caregiver perspective, is that many just don't know what's out there ... Where do I go, what do I do? … I think, at that point … it's harder to go out and seek out that information when you're in a reactive mode …” (LEI02).

Even when needed services and supports were available (not always the case), accessing and managing them took considerable time and energy.

- “There's a lot of information out there, but a lot of caregivers are not connecting to quite a lot of it and the system is extremely fragmented and some of it is not the most efficient and that's causing a lot of issues.” (LEI05)

Lacking basic dementia education, or information on how to access needed services, care partners could miss or misinterpret important warning signs. Said one care partner about the time their parent began to exit the family home,

- “Maybe the sixth or seventh time he went missing [I realized] that I needed the police. I didn't realize … I didn't connect that easily, right. Eventually, people will connect it. It's just I would have liked to have connected that maybe around number one or two incidences earlier. … I had five or six chances before I realized how serious it was. … but there are families that don't get that second chance …“ (LEI02)

Such challenges can persist throughout the care journey, leaving care partners to make on their own. Said a care partner about the day when their parent transitioned to a LTC home,

- “It's such an emotionally charged day and people are handing you papers to sign … in my case, we got my mother there, which was a feat in itself … but I'm handing my mother over to strangers and having to admit that we can no longer win the battle of keeping her in her own home independently and … she has to go now.” (LEI04)

Challenges Working with Providers

Even after accessing home and community care or transitioning to a LTC home, Lived Experience Respondents said they still faced challenges working with providers. Instead of responding to what people need, care often depends on what providers are able and willing to offer.

One key factor identified concerns the availability of workers trained in dementia and cognitive wellbeing. While workers may know basics such as dressing, toileting, and bathing, they may have little practical understanding of how to meaningfully engage with persons living with dementia and care partners. According to a person living in a LTC home,

- "I wish we would educate PSWs when we do orientation, because I found that a lot of the [staff] not knowingly will go up and just push your wheelchair without telling the person in the wheelchair that they're doing it, and it really upsets people with dementia because it's a scare …" (LEI01)

Chronic understaffing create additional challenges. Even when workers have the skills and knowledge to provide person-centred care, they might still not have the time and resources to do it. Said the same interviewee,

- "I have to tell you, these [staff] are overworked … [they] have a lot of residents to deal with. I think they go from eight to 11 residents … And it's hard, especially in the morning and they have to get people up, get them ready for breakfast, get them dressed. And then you have some people who … scratch … and they have to deal with that." (LEI01)

While person-centred care anticipates that providers will know the person and tailor care to the person's needs and preferences, this takes time. In the absence of consistent staffing, the focus can quickly shift from individual wellbeing to completing basic tasks as expeditiously as possible. One forum respondent who had worked in a primary school where they assisted with the development of individualized student learning plans, used the example of a crowded classroom to illustrate the similar challenges faced in a residential care setting.

- "The teachers had 30 or more kids in their class and trying to create a student-centered educational plan for each of those students, especially grade one where they're all over the place … Now you've got long term care they have … 12 residents on a ward [with] one nurse ... trying to make sure that they have time to care for each person. They make the beds. They have to wash, shower. Change, feed. … And they have to do this in their time slot which they never have enough time … and then to expect them to also sit down and have a little chat with the client. That never happens. They are task oriented all the time, so to get that person centered care they need more people …" (LEF06)

A lack of care standards and poor working conditions further undercut the promise of person-centred care. According to an interview participant,

- "We sent two letters out to our MPs [Members of Parliament], one for the national standards … and the other saying that the PSWs need to be better paid. Full time work with benefits. There's a PSW in Ottawa that's living in a shelter ... It just boggles my mind." (LEI05)

Competition for available workers adds further complications. One interviewee noted that workers in LTC homes typically have lower pay and benefits than those in hospitals. Thus, as hospitals recruit workers, it becomes more difficult to attract and retain qualified workers in LTC homes, let alone in the community where pay and benefits may be lower yet.

- "… the need to attract staff and to hold them … What is it that maintains someone who has gone through all of the requirements to be a staff member in long term care? And then the hospital gives them a salary and shifts that they prefer and so they're gone." (LEI04)

Such challenges are not limited to LTC. A care partner supporting a parent living with dementia in the family home said they faced numerous challenges trying to get consistent home care workers.

- "The agency, which was [a national home care provider], scheduled 12 people for 13 sessions. I was furious when I heard, because if they throw darts at a dartboard they cannot do much worse … So it's like they weren't even trying for God's sake, they just they treat people like helpless commodities." (LEI05)

Similarly, a care partner spoke of having to deal with an ever-changing line-up of workers who had little time to learn about the needs of the person they were caring for, and didn't know what other workers had done. Each time a worker changed, care plans would start from scratch.

- "I found I spent most of my time explaining to the different people who are coming into the [family] house to help keep my husband social and or active …he didn't need help showering, he didn't need help toileting, he didn't need help feeding or anything like that. He just needed someone basically to watch him and make sure he didn't wander away or get into anything that he wasn't supposed to. … I found it very frustrating because I had three different care coordinators and each one did not communicate with the following one. And then, if, for some reason, the person who would normally come into the house couldn't come into the house then it was start over." (LEF06)

Another care partner stated that even when they supported the same person, different providers and workers rarely communicated with each other.

- "My husband was involved in two day programs. And there was no communication between the two. As to why he went into the second one [it] was because the behaviour was becoming unmanageable; I knew that, but the new place did not. So I think it's really important that there is connection between whatever groups are in your, let's say your health team." (LEF04)

Similarly, a person living with dementia observed how challenging it was for them to deal with many different providers along their care journey.

- “In three years of diagnosis, I think there's probably 100 different characters that I have to deal with. There's no consistency [although] consistency is a key … You know those kinds of things are really important … having one person as a point of contact.” (LEF03)

Additional challenges are added when providers cannot communicate in the person’s first language. A forum respondent observed that this can result in persons with dementia being treated like children.

- “… a lot of people revert back to their mother tongue even though they have lived in Canada for a long time and they speak English. … In my dad's home there are some people who speak different languages …I am able to use my phone for Google translate but [residents] don't have the support … And so what often results is … the infantilization of the residents …” (LEF05)

COVID’s Added Impact

Lived experience respondents did not comment at length about the impact of the pandemic, in part because most lived in community settings where COVID’s impact had been less marked than in LTC homes. However, the experience of one interviewee, a resident of a LTC home, is worth noting. They recounted how COVID had created many hardships, including isolation and the deaths of co-residents and friends.

Observing that they had been lucky to survive, this respondent described the distressing experience of being “cohorted” for an extended period of time, effectively isolated in an unfamiliar room with few personal possessions and little contact with the outside world. This experience was made all the more difficult by a lack of information about what was going on or when isolation would end.

- “The second wave we had a few people sick … but the first wave, we lost 12 residents. And I was cohorted in a room that was not my own … so I couldn't even go into the hall to see how my peers were doing. And I think this really upset me … no one told me anything so I didn't know that some of my friends passed away … and that's really upsetting because when you make friends and you see someone every day, and you laugh, and you joke, and you go on trips together. And then, all of a sudden they're not there anymore.” (LEI01)

4.3.2 What Should Happen: Best Practices

On the positive side of the ledger, Lived Experience forum and interview Respondents identified opportunities for advancing person-centred care. Four lessons learned/best practices emerged.

Know and Value the Person

This first best practice highlights the importance of acknowledging persons living with dementia and/or behaviours/expressions, not just as recipients of care, but as whole persons with histories, interests, achievements and preferences, and with the potential not only to participate in their own care, but to make meaningful contributions to others. Knowing the person, not just their clinical needs, is essential for person-centred care.

- “Age, sex, education, that kind of stuff [is very important]. The [most important] psycho-graphics for me are your opinions, beliefs, values. …okay well your dad is a spiritual man … he loves music.” (LEI02)

A forum participant elaborated this idea.

- “… we have a situation where you know the doctor who was seeing person after person after person kind of comes in, their eyes glaze over, they look at the chart and just kind of like you know, just another kind of name on the list. And then it just happened someone mentioned that my dad played hockey … and he played “old timers” into his 70s and the doctor was like, what? You play hockey? And then suddenly the conversation completely changed. It was fascinating to see …” (LEF05)

Similarly, a person living in a LTC home suggested that instead of being seen simply as new admissions, persons moving into care homes should be welcomed as full members of their communities. Peers (e.g., other persons living in the home) should be engaged in this process, thereby easing often-difficult transitions, while validating their own capacity to contribute to others.

- “When they come into long term care, I think it would be a nice idea if they were brought by their families to go through the home and have people speak with them … the day they come in, I don't think they should be bombarded with 100 [questions] from students. I think they should get a chance to get used to the place and I think it would be nice if one of the peers could be appointed to take them through the home and show them where things are … invite them to come to residents’ council meetings ... give them a welcome basket, which we can do now, we put in toiletries and they put in a little bear.” (LEI01)

Forum and interview Respondents elaborated this idea. They suggested that person-centred care means more than just asking people what they need, although this is clearly important. It also means acknowledging and supporting the person’s variable potential to help themselves and others. For example, a resident of a LTC home stated that they used the skills and knowledge learned as a teacher to support other residents.

- "But if we ever get over this [pandemic] and I'm still alive, I would definitely like to work with [other residents] … before the pandemic I sat with this gentleman whose wife asked me if I would do some activities with them one on one and so I got some books. … so I kind of picked up some workbooks, I guess, and we did that." (LEI01)

This participant went on to say that they also educated and encouraged staff as they faced day-to-day challenges.

- "So now, I find myself in a long term care home surrounded by a lot of people who have dementia. And unfortunately, I see some of the … staff … yelling at them. And I get so upset I have to go through and say don't yell. Now I've got the staff laughing and talking with them and joking and being very supportive." (LEI01)

Along the same lines, a person living with dementia in the community talked about the value of pairing persons at different points in the care journey to provide mutual support and a sense of purpose and self-worth.

- "[In this dementia support program] you're paired up with people with dementia with lived experience. That way it's kind of like a partnership, because … you guide the person and get information [from] the person with dementia." (LEI03)

Persons with lived experience could also help, if given the opportunity, to create more person-friendly living environments. For example, one interviewee observed that grouping people together in small social units, rather than on large institutional floors, could create a stronger sense of community. Likewise, building accessible counter-tops and wider doorways could enable residents with mobility challenges to do more to help themselves and others.

- "The new homes … have small units … with eight people, and in the middle they have a dining area and the lounge area. And then at the other end they have another [unit] with another eight people. … They come together for meals and they come together for activities … [Also] having light switches at wheelchair height … Having bathrooms wide enough so that you can go in with a chair turned around." (LEI01)

Similar principles could be applied in the community. For instance, one interviewee spoke to the advantages of cooperative housing (co-housing) in which available resources (such as care workers) could be shared among people living in the same building to improve scheduling, moderate costs and strengthen connections.

- "The home care [is] $16 to $19 an hour…most medication administration was $35 to $40 an hour, with one to two hours minimum … [Or] they can potentially go in to help people get dressed and go around to help [other] people take a shower or medication.

And then come to make sure they have lunch … you can potentially keep [workers] in the same building just going around to different households." (LEI05)

The idea of mutual assistance could also be used to encourage and reward volunteers. One lived Experience participant talked about offering volunteers credits for the hours they contributed which could then be exchanged for benefits such as home-cooked meals.

- "… and what they did is say anybody volunteering more than four hours gets a meal, a home cooked meal. And so they have these elderly, maybe lonely people. And maybe those on limited income volunteer. And so with the price of a home cooked lunch they got four to eight volunteer hours. Okay, and that is absolutely fantastic value." (LEI05)

While emphasizing that there was much to do, persons living with dementia and care partners acknowledged that important progress was being made in some areas. They cited the BSO *Provincial Lived Experience Advisory* as an example of how persons living with dementia and care partners can be engaged to inform decision-making. Likewise, the *By Us for Us Guide* initiative, supported by the Murray Alzheimer Research & Education Program at the Schlegel - UW Research Institute for Aging, was cited as a constructive means of engaging people living with dementia and care partners in meaningful work and supporting others.[54] Said one interviewee,

- "… 'By Us for Us' guides. The previous [guide] was the young onset [dementia guide] which I helped with and now we're doing one currently which is going into publication right now on social isolation. … That's why it's 'By Us For Us' because it's people with dementia kind of giving their ideas on how to cope and get through …" (LEI03)

Engage and Support Care Partners

Lived Experience forum and interview Respondents also spoke to the importance of engaging with care partners and giving them the support they need to sustain their essential caring activities.

One interviewee, a care partner who had assisted a parent living with dementia, stated that care partners need to know from the start that they cannot do everything by themselves and that they should seek help, although finding help can be challenging.

- "And my joke is even Superman … is by himself the strongest guy, or Wonder Woman … they even created a team, called the justice league … you find the other superheroes you know, and all that and it's a team game, not an individual game." (LEI02)

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[54] Research Institute for Aging. By Us for Us Guides. Accessed on-line, May 2021, at https://the-ria.ca/resources/by-us-for-us-guides/

This perspective was echoed by a care partner who had accessed a support group offered by a local agency. Their experience, while positive, raised the question of how to encourage different providers and agencies to work together to make such resources more widely accessible.

- “They started a caregiver support group and I went … and that's when the Alzheimer’s [Society] people came in … my question is, there are obviously linkages that exist now between BSO and Alzheimer’s. Are there ways that those collaborative links can be enhanced? … I guess this comes back to … the importance of connections and collaboration.” (LEI04)

Education was highlighted as a crucial resource for care partners. Said one participant, providing care to a loved one is inherently challenging. But trying to do it without knowing what to expect, what resources are out there, or how to get to them, can make caring unsustainable.

- “Bridge the gap. The essential caregivers, family or volunteers, can be a bridge, but we need to be trained.” (LEI05)

A person living with dementia elaborated this idea, saying,

- “I think the educational aspect … is so important. I mean somebody becomes a caregiver… Well they go home with this person who has dementia, his or her foibles, and they have got the faintest idea what they have to deal with. But they find ways to deal with it and they're not always the right way. So anyway, there [should be] a better education process.” (LEF03)

This theme was echoed by a care partner who saw education as essential tool to support a demanding long-term role.

- “[Care giving] is not something that we've chosen to do but we are doing it, and we do it to the best of our ability. And if we can have a little bit more … education and training … it would be so helpful. (LEF06)

Of course, education should not be limited to care partners; everyone on the care team should have the skills and knowledge required to work as a team and provide person-centred care. However, for one forum participant, trends seemed to be moving in the wrong direction. They noted that, in a bid to graduate PSWs more quickly, education standards appeared to be in decline.

- “There are some generalizations that need to be learnt and that aren't taught … and they were talking about reducing the length of time that PSW's are in school. And like shortening their education. And it just frightens me because I think they're the front line people, especially for home care and in long term care and their education is already limited." (LEF 06)

Ensure Access to and Continuity of Care

A third best practice aims to improve access to, and continuity of care. Instead of having to search for the right resources, particularly when things are at their worst, persons living with dementia and care partners should have a single point of contact that they can use throughout the care journey. One forum respondent observed,

- "A single point of contact … through to end-of-life, so that everyone gets to know each other and so that, rather than it being crisis, when people are at their very worst … To use a personal example, my father was very physically active. … my family took him out, we took him out every day for a walk. But, in the middle of the night, they decided that if he would get up, they would just call the police … You know, we had no one to call to say this is ridiculous. We talked to the representative from the care home and their answer was like don't worry about it, you don't have to pay for the ambulance … That was the only concern that they could understand. … But if we had had someone, we could say, should my dad be sent to the hospital like on a weekly basis? … But we had nobody to contact, so I think I love this idea of the care teams across the care settings." (LEF05)

Another participant linked this idea to the work of BSO mobile teams and their ability to connect different providers and care settings.

- "I wish that there was a way that there could be that ongoing regular contact that could at least provide a little bit of comfort and security … [but] BSO teams, at least the mobile teams, were short term which breaks my heart a little bit because you wish that you could continue on and not have to go, okay great you know we've managed these challenging issues, and now the case can be closed …" (LEF01)

Access to care records also emerged as an issue. One forum participant who had experienced difficulty finding out how a family member had been diagnosed and treated, emphasized the importance of care partners and families being able to access care records. In addition to learning what providers had seen and done, such access to information and records could promote communication, collaboration and continuity of care.

- "I'll jump in here and add one of the things that I would like to see as part of the conversation … the notion that people have access to their own health records. I think that would you know, help mitigate some of the communication gaps … from a family perspective it's not so much that we don't trust people or we want to judge them. It's that everyone has a lot of work to do and it's like you know, if everyone is working together and helping each other and everyone has different pieces of the information, if it can all be shared in a way." (LEF04)

Start Early

A fourth best practice highlights the importance of engaging as early as possible in the care journey. Rather than being reactive and trying to manage problems after they have advanced to the crisis point, the better way is to be proactive, to know and value the person, to engage and support care partners as early as possible in the care journey. A comment by a forum participant captures this idea,

- "I do feel like we need to be more proactive and preventative in our work. … Family members, staff members, everybody who is caring for somebody who has dementia. I really think it needs to start back in the community … the dream would be for people to think about this, even before a diagnosis. … capture a little bit of their life story in a video … so that that can be an educational tool, no matter where the person goes in their journey, whether it's in hospital, long-term care, retirement home, I want it to be accessible to anybody who's involved in the person's care with the person and their family's consent." (LEF01)

Ideally, education for care partners should begin early, soon after diagnosis, so that they, along with other members of care teams, know what comes next and what they can do about it.

- "[At first diagnosis] the caregiver person who was going to be looking after them [should be] given [education] immediately … a considerable amount of education. That would be important. And that education cannot be limited just to caregiving. It's kind of neat for all other professionals." (LEF03)

5.0 Summary

This report, the third in a series commissioned by the BSO Provincial Coordinating Office (PCO), draws on multiple evidence sources to evaluate the work and impact of BSO prior to and during the COVID-19 pandemic. Evidence sources include:

- Two hundred and sixty nine qualitative stories written by BSO teams across Ontario between 2018 and 2020
- Key Informant interviews with 20 BSO team members and collaborators conducted in late 2020 and early 2021
- Findings from a Lived Experience forum and individual interviews involving a total of 13 persons living with dementia and care partners conducted in the spring of 2021.

In addition, this report is informed by the findings of two previous evaluation projects completed in 2018, one a review of previous evaluation findings and the other a detailed analysis of BSO qualitative stories written between 2015 and 2018. Together these evidence sources paint an exceptionally detailed portrait of the work and impact of BSO, not just at one point in time, but over five years, a period characterized by rising and more complex population needs and by care systems struggling to respond even prior to the COVID-19 pandemic.

In the sections below we summarize key findings from each of the three evidence sources used, along three common dimensions: demand-side trends and issues; supply-side trends and issues; and lessons learned/best practices.

5.1 What We Found: Highlights

5.1.1 Qualitative Stories

The qualitative stories provide detailed first-hand accounts, by BSO team members, of experiences in day-to-day practice.

Demand-side Trends and Issues

As detailed in Section 4.1, the stories invariably put the “person” at the centre of BSO work. In contrast to 2018, when we distinguished responsive behaviours/personal expressions from needs – aiming to highlight both – in this report we bring them together, reflecting the incisive observation of one story-writer that “behaviours don’t define a person” and that both are integral to knowing and appropriately supporting the person.

Confirming what we observed in 2018, the more recent stories reveal that needs and behaviours/expressions are extremely diverse and complex.

With respect to needs, whereas BSO emerged largely to support older persons living with dementia, the stories show that BSO clients now include persons of all ages living with dementia, mental illness, substance use, and/or other neuro-cognitive conditions, in combination with multiple chronic health needs (e.g., cancer, arthritis, heart disease, addictions), social deficits (e.g., poverty, family distress, social isolation) and the compounding effects of inadequate or inappropriate health system responses (e.g., inappropriate prescribing, failure to diagnose and treat conditions such as chronic pain). Added to this mix is growing diversity in areas such as language, culture, religion and sexual orientation. In sum, since its inception, the volume and complexity of needs and behaviours/expressions reported by BSO teams has risen, and continues to rise, exponentially.

The stories also show that responsive behaviours/personal expressions span a wide spectrum ranging from wandering/exploring and withdrawal with lower associated risk, to verbal and physical behaviours/expressions with greater risk. Moreover, individuals may present with different behaviours/expressions at different points in time, or multiple behaviours/expressions simultaneously.

The stories further clarify that care partners, when present, are rarely bystanders. During the course of the pandemic, their “essential” role in community and residential care settings has been increasingly visible and acknowledged by providers and policy-makers. In addition to offering ongoing personal, instrumental and emotional support, care partners continue to fill gaps resulting from worker shortages and service disruptions, and they contribute as active participants on care teams. Just as importantly, the stories emphasize that in doing this, care partners require support in their own right to sustain their caring activities.

Supply-side Trends and Issues

The qualitative stories document widening care gaps resulting from escalating needs but insufficient system capacity to meet needs. In addition to impacting negatively on the wellbeing and quality of life of persons living with responsive behaviours/personal expressions and care partners, such gaps can be costly and disruptive for providers and care systems. While “hallway medicine” has become one of the most visible indicators of care systems at their limits, the qualitative stories suggest that stretched system resources can contribute to less visible, but equally weighty dilemmas, such as over-reliance on the use of drugs to manage behaviours/expressions.

In this demanding context BSO plays a pivotal role. The stories document how BSO mobile and embedded teams reach across professional, organizational and geographic boundaries to support persons with complex, chronic needs and behaviours/expressions in the most appropriate care settings, while smoothing transitions between care settings when they are needed. Even within fragmented care systems, BSO teams thus work to integrate care around persons who might otherwise “fall through the cracks” leading to unnecessary hospital and LTC home admissions.

The stories also document BSO’s crucial role in mobilizing knowledge and best practices to improve care and build system capacity. In addition to promoting the use of validated, standardized tools such as the BSO DOS [Dementia Observation System], BSO creates local, regional and provincial platforms for education and knowledge exchange.

Lessons Learned/Best Practices

The qualitative stories yield six lessons learned/best practices that strongly align with BSO’s mission to create a quality-driven, sustainable support system of person-centred care for those living with, or at risk of developing, responsive behaviours/personal expressions.

Five of these are essentially similar to, and reinforce, lessons learned/best practices identified in 2018. They emphasize the importance of person-centred care; engagement of family and care partners; inter-disciplinary and inter-sectoral collaborations; managed transitions between care settings; and knowledge mobilization and capacity building.

A noteworthy addition is “balancing pharmacological and non-pharmacological approaches.” This reflects the perception that there is an over-reliance on the use of drugs to manage responsive behaviours/personal expressions, and that such use, when not evidence-informed and closely monitored, may cause harm including escalation of the behaviours/expressions they are meant to moderate. Instead, this lesson learned/best practice points to a re-balancing of pharmacological and non-pharmacological approaches toward the latter. As the stories document, BSO teams are particularly well-equipped to do this drawing on a growing body of evidence and best practices to design and deliver person-centred interventions that are less reliant on drugs.

5.1.2 Key Informant Interviews

The Key Informant interviews elaborate and extend these findings.

Demand-side Trends and Issues

The interviews point to a disquieting “new normal.” While the qualitative stories detail discrete cases of persons living with complex needs and responsive behaviours/personal expressions, Key Informants, with their broader view, suggest that such cases are increasingly the norm in all care settings across the province. Said one Key Informant, “whereas it used to be a nursing home full of little old ladies who were gentle and quiet and proper … [now] we see kicking, fighting, screaming …” (KI12).

Nor, as suggested in this quote, is it only “little old ladies.” Increasingly, BSO teams support younger persons living with complex, chronic needs including developmental delays, physical disabilities, autism, mental health and substance use, as well as dementia and neuro-cognitive conditions.

Supply-side Trends and Issues

While demographic shifts and medical advances partly account for this trend, Key Informants clarified that supply-side factors also play a crucial role. They observed, for example, that while in the past persons living with mental illness often received care in institutional settings, successive waves of “de-institutionalization,” without a corresponding expansion of community-based alternatives such as supportive housing, had made LTC homes the default destination for growing numbers of younger persons with complex needs and behaviours/expressions.

According to Key Informants, the COVID-19 pandemic layered on new challenges. In the community, programs and services were curtailed, home visits were no longer feasible, and care partners faced rising burden and burnout. Here, BSO teams pivoted to using virtual technologies (e.g., OTN, Zoom) to conduct assessments, assemble care teams, and provide education and support to persons, care partners and providers. Such approaches, while not always a preferred option, greatly extended BSO's scope and reach, particularly in underserved northern areas of the province as well as inner cities.

In LTC homes, where the majority of COVID-related deaths occurred during the pandemic's first wave, BSO teams applied their specialized skills and knowledge to support residents and staff impacted by worker shortages, service disruptions, isolation, depression, loneliness, the deaths of co-residents, and restrictions on visits by care partners. Although frequently called "to the floor" to perform routine tasks, BSO teams continued to reach out to external partners such as local health units to support residents and mitigate behaviours/expressions such as wandering and tobacco use that now posed infection control risks. Paradoxically, Key Informants reported that in some LTC homes, behaviours/expressions actually declined during the pandemic as a result of reduced noise and fewer residents sharing rooms.

Lessons Learned/Best Practices.

Key Informants strongly reaffirmed the importance of person-centred care, not simply as a frill, but as an essential means of understanding and responding appropriately to increasingly complex needs and behaviours/expressions among persons of all ages. Rather than suggesting that BSO mobile or embedded teams are better equipped to do this, Key Informants clarified that both mobile and embedded teams are essential to meet existing and new needs.

Added lessons emerge regarding the use of virtual technologies. Particularly since the onset of the pandemic, Key Informants said they increasingly use technologies to conduct assessments and enable collaboration, teamwork, and capacity-building. In key areas like mental health, virtual technologies have enabled access to specialized expertise that might not otherwise be accessible. Virtual technologies have become, and will remain, an essential tool in the BSO toolkit. Of course, this raises new questions of how best to ensure that all persons that require support, including those with limited resources, have access to needed technologies. While offering many advantages, reliance on technologies can also create inequalities in access to care.

5.1.3 Lived Experience Forum and Interviews

The results of the Lived Experience forum and interviews add a crucial perspectives to the evaluation findings. They document how persons living with dementia and care partners perceive their needs, the responses of providers and care systems, and what should be done to ensure person-centred care.

Demand-side Trends and Issues

Lived Experience forum and interview Respondents said that full awareness of their needs had emerged slowly. For example, a person living with dementia spoke about realizing that the memory issues they experienced were not a normal part of aging. Similarly, a care partner spoke about realizing that exit-seeking by a family member was rooted in dementia, and that it posed risks. However, for the most part, Lived Experience Respondents took their needs as given: they focused on the challenges experienced as they attempted to access care.

Supply-side Trends and Issues

For example, Lived Experience Respondents said they had struggled even to get providers to listen to them and obtain an accurate diagnosis. Following diagnosis, they were left on their own to navigate convoluted care systems where different providers, programs and services all worked independently and with little communication between them. Obstacles included ever-changing casts of workers who rarely coordinated their efforts and who, because of a lack of education or time, tended to focus more on completing tasks than engaging with persons living with dementia and care partners to understand and address their needs. Access to health records also posed problems, as providers controlled, and sometimes withheld, crucial information. To get needed support, Respondents had had to confront providers, a particularly daunting challenge for persons living with dementia and care partners.

Lessons Learned/Best Practices

Lessons learned/best practices from Lived Experience Respondents accordingly underscore the importance of “person-centred care,” that is, care that takes into account the values, preferences, histories, interests, and achievements of persons living with dementia and care partners, as well as clinical needs. Whereas persons living with dementia and care partners may sometimes be treated as passive recipients of care with decisions made on their behalf by well-meaning experts, Lived Experience Respondents asserted that that they wished to be acknowledged as full participants in decisions affecting their lives with the potential to contribute to others.

In this connection, Lived Experience Respondents emphasized the crucial importance of early diagnosis and connections to care to ensure that appropriate resources, including education, are accessible as soon as possible. To facilitate this, all providers, from front-line workers to medical experts, should be educated to understand the principles of person-centred care and how these principles should be applied on a day-to-day basis.

Further, Respondents said that their potential to make meaningful contributions to others should be recognized and supported. For example, a person living with dementia talked about the benefits of pairing persons at different points along the care journey to provide peer-to-peer support. Similarly, a LTC home resident talked about tapping into past professional training and lived experience of residents to support other residents and staff. Respondents also talked about the valuable insights that persons with lived experience could bring to the design of person-friendly care environments. The work of the *BSO Provincial Lived Experience Advisory* and the *By Us For Us Guides* initiative were cited as examples of how persons with lived experience can tap into that experience to assist themselves and others. While the

Advisory generates advice for providers and policy-makers,[55] the *By Us For Us Guides* initiative engages persons living with dementia and care partners to create accessible guidebooks for peers "to enhance their well-being and manage daily challenges."[56]

6.0 Recommendations

Informed by these findings, we offer three recommendations for BSO work going forward. To set the stage, we begin by briefly reviewing our recommendations for 2018 and then indicate how our 2021 recommendations have changed.

6.1 What We Recommended in 2018

In 2018 our recommendations were:

- Reaffirm person-centred care as a core value
- Strengthen the evidence-base
- Advance knowledge-mobilization and capacity-building.

Consistent with BSO foundational principles, this first recommendation located the person at the centre of all BSO work. We noted that, "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."[57]

The second and third recommendations emphasized the importance of knowledge creation and knowledge mobilization as key means of advancing person-centred care. Here, we proposed that BSO continue to use its extensive province-wide networks to gather evidence and intelligence about changing needs, best practices and innovations in care, as well as establishing outcome metrics and performance indicators. Further, BSO should continue to expand its networks to ensure that such evidence and intelligence is put in the hands of those who can best use it to improve care and build system capacity.

6.2 What We Recommend in 2021

In 2021 we build on these recommendations. We also add a sense of urgency.

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[55] brainXchange. Provincial Lived Experience Advisory Network. Accessed on-line, June 6 2021, at https://brainxchange.ca/BSOProvincial-Lived-Experience-Advisory-Network

[56] brainXchange. By Us For Us Guides. Accessed on-line, June 6 2021, at https://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Caregiver-Care-Partner-Support-and-Resources/By-Us-For-Us-Guides

[57] Morton Chang F, Williams AP. 2018. Behavioural Supports Ontario (BSO): Review of Qualitative Stories. Accessed on-line, June 2021 at https://behaviouralsupportsontario.ca/Uploads/ContentDocuments/2019-07_BSO_Review_of_Qualitative_Stories.pdf

For decades it has been widely acknowledged that an aging population and an associated rise in complex chronic health and social needs would challenge fragmented health care systems. In Ontario, the persistence of "hallway medicine" has been linked directly to the fact that persons with multiple needs can "fall through the cracks" and end up in inappropriate care settings such as acute care hospital beds even when such costly care is not required and may add to decline.

The evidence presented in this evaluation suggests the rise of a troubling "new normal." First-hand accounts from BSO teams across Ontario document not only the growing complexity of needs and responsive behaviours/personal expressions in all care settings, but the fact that these are no longer associated only with older persons. This "new normal" includes growing numbers of persons of all ages who live with multiple, overlapping needs and behaviours/expressions that push providers and care systems to their limits. In this context, scaling and spreading successful initiatives, like those led and supported by BSO, seems increasingly urgent.

6.2.1 Recommendation 1: Aspire to Person-Directed Care

As noted, our first recommendation in 2018 reaffirmed the BSO core value of person-centred care and BSO's considerable success in achieving such care. In 2021, prompted particularly by the findings of the Lived Experience forum and interviews, we recommend that BSO and its partners aspire to "person-directed care."

For its part, "person-centred care" has been described in terms of altruistic experts providing care that is "respectful of and responsive to the preferences, needs, and values" of the individual, "ensuring that the care recipient's values guide all clinical decisions."[58] In addition to equipping "patients/clients/consumers" with better education so that they can be more informed about care options, person-centred care "gives priority to outcomes that are important to the patient [sic] — such as quality of life — over technical and process measures."

By comparison, "person-directed care" contends that individuals requiring care can and should exert some degree of control over the context and content of that care, to the extent of their abilities, with knowledgeable experts playing a facilitating role. This anticipates a subtle, but important shift in the balance between professional expertise and lived experience, toward the latter. [59]

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[58] Lines LM, Lepore Michael, Wiener JM. 2015. Patient-centered, Person-centered, and Person-directed Care They are Not the Same. Medical Care. Medical Care: July 2015 - Volume 53 - Issue 7 - p 561-563. Accessed on-line, June 6, 2021 at https://journals.lww.com/lww-medicalcare/Fulltext/2015/07000/Patient_centered,_Person_centered,_and.1.aspx

[59] Pioneer Network. 2011. Continuum of Person-Directed Culture. Accessed on-line, June 29 2021, at https://www.pioneernetwork.net/resource/continuum-of-a-person-directed-culture/

Pioneered in the disability community, the concept of person-directed care asserts that service users are uniquely qualified to determine what they need and how it should be provided. However, this is not an “either/or” scenario. It recognizes that individuals living with multiple needs will require appropriate support to set goals, make good decisions, build supportive relationships and contribute to community life.[60]

Such concepts are closely aligned with established and emerging approaches to care that highlight the psycho-social, relational, and emotional dimensions of “personhood.”[61] In addition to considering *what* is done, personhood also considers *how* it is done. This includes respecting and leveraging individual capacity to express preferences, build relationships and engage in care decisions to the extent possible.[62]

These concepts align with the highly influential work of the World Health Organization (WHO). In its Alma Ata declaration of 1978,[63] the WHO emphasized that “people have a right and duty to participate individually and collectively in the planning and implementation of their health care.” Such participation is seen both as a means of making better decisions, since people and communities are most knowledgeable about the challenges facing them, and as an end in itself, since individual control and empowerment are themselves key determinants of health. In its recent vision for the global “Decade of Healthy Ageing” (2020-2030), the WHO asserts that all persons, “without distinction of any kind,” have a right to the highest attainable standards of physical and mental health along with the right to participate in broader “public, political and cultural life.” [64]

To be clear, our first recommendation does not anticipate the adoption of a particular funding or delivery model. Rather, it highlights the importance of the work that BSO and partners are already doing to engage persons and care partners as active participants in their own care, and to support their contributions to the broader community.

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[60] Corbrook, Family Service Toronto, Griffin Centre, et al. 2016. A Facilitator’s Guide to Person Directed Planning. Accessed on-line, November 2021, at https://familyservicetoronto.org/wp-content/uploads/2016/03/A_Facilitators_Guide_to_Person_Directed_Planning_6.pdf

[61] Kitwood T. 1997. Dementia reconsidered: The person comes first. Berkshire, UK: Open University Press.

[62] Williams AP. 2018. Backgrounder: IHPME Centre for Patient and Caregiver Engagement. Institute for Health Policy, Management and Evaluation, University of Toronto.

[63] World Health Organization. Declaration of Alma Ata. September, 1978. Accessed on-line, June 2021, at http://www.euro.who.int/en/publications/policy-documents/declaration-of-alma-ata,-1978.

[64] World Health Organization. Decade of Healthy Ageing 2020-2030. 2020. Accessed on-line, November 2021, at https://cdn.who.int/media/docs/default-source/decade-of-healthy-ageing/final-decade-proposal/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_25&download=true

For example, The BSO *Provincial Lived Experience Advisory* and *By Us For Us Guides*[65] initiatives were offered as concrete examples of how persons and care partners can draw on their lived experience to educate and support peers and provide decision-makers with essential insights into needs and the value of different approaches to meet needs.

Other opportunities include pairing LTC home residents for mutual support; drawing on previous professional training and experience to support peers and staff; and engaging residents in designing person-friendly environments. Although not every person and care partner will be willing or able to participate in these particular ways, the goal is to encourage active engagement in personal and community life to the extent possible at all points along the care journey. In addition to improving care, this can nurture a sense of self-worth and purpose, affirm personhood, and strengthen communities.

Our first recommendation thus anticipates that these and similar initiatives will be scaled and spread so that persons and care partners are enabled to engage actively in their own care and contribute to their communities, to the extent possible, with support from providers.

6.2.2 Recommendation 2: Bolster Collaboration

Of course, aspiring to person-directed care rings hollow if care is not accessible. While collaborations that reach across disciplinary, organization and geographic boundaries cannot generate resources out of thin air, they can do much to ensure that available resources are used to the best possible advantage.

The importance of this recommendation is heightened by the experience of the pandemic. It is now widely recognized that individuals and communities experiencing overlapping, intersectional needs and risks related to age, sexual orientation, race, poverty, and disability, live with inequitable and often inadequate access to health and social supports. The weight of evidence in this evaluation suggests that this is equally true for persons living with responsive behaviours/personal expressions and care partners who likewise experience multiple, overlapping needs and risks, and confront sometimes formidable barriers to care in fragmented and increasingly-stretched care systems.

The qualitative stories offer numerous examples of successful collaborations initiated and/or supported by BSO teams to address complex needs and risks. Within community support agencies, hospitals and long-term care homes, BSO teams engage with physicians, nurses, pharmacists, therapists, social workers, nutritionists, recreational staff, and PSWs, among many others including police and housing providers. Reaching across institutional boundaries, BSO

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[65] Research Institute for Aging. By Us For Us Guides. Accessed on-line, November 2021, at https://the-ria.ca/resources/by-us-for-us-guides/

teams bridge gaps between hospitals, mental health facilities, mental health outreach teams, developmental services, geriatric psychiatry and addictions specialists, as well as community support agencies, Alzheimer Societies, housing providers, faith organizations, police and other first responders. Even within otherwise fragmented care systems, BSO collaborations are thus uniquely positioned to deliver integrated, person-centred care to those who need it most.

Nevertheless, according to Key Informants, such initiatives, while long advocated, remain the exception. Although cautioning against overlapping initiatives (a problem that can itself be mitigated through collaboration), Key Informants saw collaboration as an essential tool for meeting current and future needs. They also recognized the important work done by BSO to advance collaboration.

Perhaps the most compelling arguments for collaboration come from persons with lived experience. Even for those participating in this evaluation, who are comparatively knowledgeable and assertive, care systems can be notoriously difficult to access and navigate. In addition to adding burden and stress, this increases the odds that they will fail to get the care they require, spurring decline and potentially avoidable hospital and LTC home admissions.

Our second recommendation thus anticipates that BSO will continue to leverage its unique capacity to initiate and grow interdisciplinary and inter-organizational collaborations across the province.

6.2.3 Recommendation 3: Mobilize Knowledge and Build Capacity

Knowledge mobilization and capacity-building are foundational pillars of BSO. While initially focused on “the growth of care teams through the transfer of new knowledge and the implementation of best and emerging practices,” the evaluation findings suggest that these pillars apply equally to persons living with responsive behaviours/personal expressions and care partners, as well as policy-makers.

The qualitative stories, Key Informant Interviews, and Lived Experience findings emphasize that persons and care partners, while increasingly recognized as active participants in care decisions, may not always be adequately prepared to understand their needs or care options. Relevant knowledge and best practices offered in accessible, person-friendly ways such as guides written for peers by persons with lived experience, alongside counselling, education and support by experts, were cited as vital resources for improving individual care and building robust system capacity.

Moreover, as the experience of the pandemic has shown, policy-makers increasingly insist that decisions about resource deployment (e.g., tests and vaccinations), must be “evidence-informed.” In the post-pandemic era, as needs continue to rise, but emergency resources are scaled-back, policy-makers and providers will face even tougher choices about where available resources should be invested. Getting accessible, policy-relevant evidence proactively into their hands will be all the more vital, especially when the needs of marginalized and less visible populations, such as persons living with responsive behaviours/personal expressions and care partners, are on the line.

We note that the grounds for public sector decision-making are becoming more inclusive. For example, the Canadian government now uses an approach to budgeting that explicitly considers the differential impact of spending decisions on historically marginalized groups such as women. Titled GBA+ (Gender-based Analysis Plus), this approach recognizes that “all individuals have multiple identity factors that intersect to make them who they are, for example, race, national and ethnic origin, Indigenous origin or identity, age, sexual orientation, socio-economic condition, place of residence and disability.”[66] GBA+ is now being used “to systematically incorporate important diversity considerations” into decision-making not just with respect to budgeting, but more generally.[67] Such considerations apply equally to persons living with responsive behaviours/personal expressions and care partners most of whom also experience overlapping, intersectional needs and risks. To make informed decisions, decision-makers need to know how these needs and risks should be taken into account.

In areas characterized by great complexity, where needs are overlapping, interventions may be combined, and outcomes are not always clear-cut, “performance reports” drawing on first-hand “stories” as well as other evidence sources, can provide in-depth insight into what works, what doesn’t, and why. Especially when such reports are recurrent, they can identify emerging trends and issues, as well as lessons learned, in real time.[68]

Here, BSO’s work is well advanced. In addition to drawing on relevant scientific evidence, and best practices nationally and internationally, BSO is uniquely positioned to document what happens across the care continuum, across the province, and over time, informed by the first-hand perspectives of persons with lived experience and BSO team members. Particularly with the addition of lived experience, BSO and its collaborators now have access to a multi-year, multi-source evidence base that documents the pace and direction of change on both demand and supply-sides, and the success of different approaches for improving care.

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[66] Government of Canada. What is Gender-based Analysis Plus? Accessed on-line, June 2021, at https://women-gender-equality.canada.ca/en/gender-based-analysis-plus/what-gender-based-analysis-plus.html

[67] Government of Canada. Apply Gender-based Analysis Plus to your work. Accessed on-line, June 2021, at https://women-gender-equality.canada.ca/en/gender-based-analysis-plus/apply-to-work.html

[68] Thomas P. 2006. Performance Measurement, Reporting, Obstacles and Accountability: Recent Trends and Future Directions. The Australian National University. Accessed on-line, June 2021, at https://www.researchgate.net/publication/328522788_Performance_Measurement_Reporting_Obstacles_and_Accountability_Recent_Trends_and_Future_Directions

We suggest that also adding the perspectives of partners and collaborating organizations to this evidence base would provide valuable insight into how BSO is seen by others, and how its efforts, particularly those aimed at advancing collaboration and building capacity, can be bolstered at individual, organization and systems levels.

Our third recommendation thus anticipates that BSO will continue to grow its efforts to build and mobilize the evidence base in the post-pandemic era.

Concluding Comment

In conclusion, we think it appropriate to repeat our observation made earlier.

In spite of the extraordinary demands of the pandemic, and the different perspectives represented in each of the three evidence sources used, a strong and consistent message emerged: in a period of rising and more complex needs, and care systems that struggled to meet needs even prior to the pandemic, the work of BSO and its readiness to take on the most complex challenges at individual, organization and systems levels, are all the more essential. The real question, from provider and user perspectives alike, is how to scale and spread this important work.