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

Executive Brief

December, 2021

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Acknowledgements

We sincerely thank the Qualitative Story writers, Key Informants and Lived Experience Respondents from across the province and care continuum, who generously shared their time, expertise and insight to inform this evaluation. Their dedication to enhancing the wellbeing, quality of life and choice for persons living with behaviours/expressions, and care partners, is inspiring.

Full Report Available

This Executive Brief summarizes the findings of the more extensive and detailed Full Report available on-line at https://www.behaviouralsupportsontario.ca/

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, responsive behaviours/ personal 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 in congregate settings, and care systems.[3]

What We Did

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. As detailed in our Full Report, 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 from all regions of the province, different care settings and diverse professional/occupational groups, 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 evaluation projects completed in 2018, one a review of earlier evaluation findings[4] and the other a detailed analysis of BSO qualitative stories written between 2015 and 2018.[5] Together these evidence sources paint an exceptionally detailed portrait of the work and impact of BSO, not just at one point in time, but

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

over five years, a period characterized by rising and more complex needs and care systems struggling to respond even prior to the COVID-19 pandemic.

What We Found

Qualitative Stories

The 269 qualitative stories analyzed provide detailed first-hand accounts, by BSO team members, of experiences in day-to-day practice.

Demand-side Trends and Issues

The stories confirm that needs and responsive behaviours/personal expressions are highly complex, that they occur in all care settings, and that they are not limited to older adults. BSO clients increasingly include younger persons living with dementia, mental illness, substance use, physical disabilities, and/or other neuro-cognitive conditions, often in combination with multiple chronic health needs (e.g., cancer, arthritis, heart disease), social deficits (e.g., poverty, family distress, isolation) along with the compounding effects of inadequate or inappropriate health system responses (e.g., inappropriate prescribing, failure to diagnose and treat underlying conditions such as chronic pain). Added is growing diversity in areas such as language, culture, religion and sexual orientation.

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

The stories also clarify that care partners (including family, friends and neighbours), 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 care, instrumental and emotional support, care partners fill gaps resulting from worker shortages, service disruptions and care fragmentation. Care partners also provide vital insights into the person’s needs, preferences and behaviours/expressions. In doing this, care partners can themselves take on burden and stress, requiring ongoing support in their own right to sustain caring activities.

Supply-side Trends and Issues

The qualitative stories document widening care gaps. While “hallway medicine” has become the most visible indicator of a healthcare system at its limits, the stories suggest that increasingly stretched system resources also 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, the stories document how BSO mobile and embedded teams reach across professional, organizational and geographic boundaries to support growing numbers of persons of all ages with complex needs and behaviours/expressions in the most appropriate care settings, and to ease transitions between settings when needed. Even within fragmented care systems, BSO teams are uniquely positioned to integrate care around the needs of persons who might otherwise "fall through the cracks" leading to unnecessary hospital and LTC home admissions.

The stories also document BSO's pivotal role in mobilizing knowledge and best practices. In addition to promoting the use of validated, standardized tools such as the BSO-DOS (Dementia Observation System), BSO has created local, regional and provincial platforms for education and knowledge exchange to improve care and build organizational and system capacity.

Key Themes/Dimensions

Analysis of the qualitative stories yields nine key themes/dimensions:

- *Dimension 1: The Person,* documents the increasingly diverse characteristics, needs and responsive behaviours/personal expressions of BSO clients and care partners
- *Dimension 2: First Contact with BSO*, confirms that initial contacts with BSO occur across the care continuum in community, hospital and LTC home settings
- *Dimension 3: Care Providers and Care Partners*, highlights inter-disciplinary, inter-organizational and sector-spanning collaborations, often including care partners, that respond to rising and more complex needs wherever they occur
- *Dimension 4: Transitions*, illuminates BSO efforts to ease often challenging moves between care settings when such moves are necessary
- *Dimension 5: BSO Initiatives,* details multiple approaches and innovations used by BSO to improve care for individuals and build system capacity
- *Dimension 6: Balancing Pharmacological and Non-Pharmacological Approaches*, describes initiatives by BSO teams to reduce over-reliance on drugs to manage responsive behaviours/personal expressions
- *Dimension 7: Impact,* documents the benefits of BSO initiatives for individuals, organizations and care systems
- *Dimension 8: New Challenges in the Time of COVID-19*, recounts the pandemic's costs and consequences for people and providers along with BSO efforts to address them
- *Dimension 9: Lessons Learned/Best Practices*, highlights the importance of person-centred care, care partner engagement, inter-disciplinary and inter-sectoral collaboration, managed transitions, knowledge mobilization and capacity building, and balancing pharmacological and non-pharmacological approaches.

Lessons Learned/Best Practices

While almost all of these lessons learned/best practices were previously identified in 2018, *Balancing Pharmacological and Non-pharmacological Approaches* stands out as a new addition. This reflects a perception among BSO team members that there is an over-reliance on the use of drugs to manage responsive behaviours/personal expressions, particularly in hospital and LTC settings. Further, where such use is not evidence-informed and closely monitored, reliance on drugs may do more harm than good including escalating the behaviours/expressions they are intended to manage.

Key Informant Interviews

Key Informant interviews with 20 BSO team members extend and elaborate 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, in all parts of 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 is it only "little old ladies." Increasingly, BSO teams support younger persons living with complex, chronic needs including developmental delays, physical disabilities, autism, mental illness and addictions, as well as dementia and neuro-cognitive conditions.

Supply-side Trends and Issues

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

The COVID-19 pandemic layered on new challenges. In the community, programs and services were shuttered, home visits ended, and care partners faced rising burden and stress even as their own supports were curtailed. In response, BSO teams pivoted to using virtual technologies (e.g., OTN, Zoom) to conduct visits, assemble teams, and provide education and support. Such approaches, while not always a preferred option, greatly extended BSO's scope and reach, especially in underserved northern areas of the province as well as in 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 address behaviours/expressions such as wandering/exploring and tobacco use that posed serious 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 a best practice and an essential means of understanding and responding appropriately to the increasingly complex needs and behaviours/expressions of 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 new needs.

An additional lesson learned highlights the use of virtual technologies. Particularly since the onset of the pandemic, Key Informants said they had increasingly used such technologies to conduct assessments and enable collaboration, teamwork, and capacity-building. In key areas like mental health, virtual technologies can enable access to specialized expertise that might not otherwise be accessible at the local level. This raises the question of how best to ensure that all persons requiring specialized support, have access to virtual technologies.

Lived Experience Forum and Interviews

The Lived Experience Forum and individual interviews document how persons living with dementia and care partners perceive their needs, the responses of providers and care systems, and should be done to ensure person-centred care.

Demand-side Trends and Issues

Lived Experience Respondents said that full awareness of their needs had emerged slowly. A person living with dementia spoke about realizing that their memory issues were not a normal part of aging. A care partner talked about coming to the realization that exit-seeking by a family member was an expression of dementia and that it posed risks. However, for the most part, Lived Experience participants took their needs as given; instead, they focused on the challenges experienced as they attempted to access care.

Supply-side Trends and Issues

Lived Experience Respondents said that accessing the resources they needed often proved challenging; obstacles appeared early and continued throughout the care journey. 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 understanding and addressing the person's needs. Access to health records could pose problems, as providers controlled, and sometimes withheld, crucial information. To get the support they required, Respondents had had to confront providers, a particularly daunting challenge for persons living with dementia and care partners.

Lessons Learned/Best Practices

Lived Experience forum and interview Respondents strongly affirmed the importance of person-centred care and strategies/opportunities for advancing this best practice including: knowing and valuing the person; engaging and supporting care partners; ensuring access to and continuity of care; and starting early.

Respondents highlighted that person-centred care should take into account the values, preferences, histories, interests, and achievements of the person as well as their clinical needs. While decisions were often made for them by providers, Lived Experience Respondents said they wished to be full participants in decision-making. In this connection, all providers, from front-line workers to medical specialists, should be educated in the principles and practice of person-centred care.

Further, Respondents emphasized that their own potential to make meaningful contributions to themselves and 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 their professional training and lived experience to support other residents and staff. They also talked about the valuable insights that persons with lived experience could bring to the design of person-friendly care environments. In this connection, they highlighted the work of the *BSO Provincial Lived Experience Advisory* and the *By Us For Us Guides* project – two initiatives that engage persons living with dementia and care partners – as concrete examples of how persons with lived experience can assist peers to manage daily challenges, and provide real-world insight for providers and policy-makers about what works, what doesn't and why.[6] [7]

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

[7] 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/

Recommendations

Informed by the findings of our 2018 reports, and findings from the multiple evidence sources analyzed in this report, we offer three recommendations for BSO's work going forward.

Recommendation 1: Aspire to Person-Directed Care

Our first recommendation in 2018 reaffirmed the BSO core value of person-centred care. In 2021, prompted particularly by the findings of the Lived Experience forum and interviews, we recommend that BSO and its partners look further toward "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. Here, experts continue to play the lead role. Person-centred care "gives priority to outcomes that are important to the patient [sic] — such as quality of life — over technical and process measures."[8]

By comparison, *person-directed care* contends that individuals receiving care can and should exert some degree of control over both the context and content of that care, to the extent of their abilities, with experts playing a supporting role. This anticipates a subtle but important shift in the balance between clinical expertise and lived experience, toward the latter.[9]

Pioneered in the disability community, 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. [10]

Such concepts are closely aligned with established and emerging approaches to care that highlight the psycho-social, relational, and emotional dimensions of "personhood."[11] In addition to considering *what* is done, personhood also considers *how* it is done. This includes

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[8] 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

[9] 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

[10] 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/

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

respecting and leveraging individual capacity to express preferences, build relationships and engage in care decisions to the extent possible.[12]

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.

For example, The BSO *Provincial Lived Experience Advisory* and *By Us For Us Guides*[13] 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.

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 access to health and social supports. The weight of evidence in this evaluation suggests that this is equally true for persons living with responsive

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

[13] 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/

behaviours/personal expressions and care partners who likewise experience multiple, overlapping needs and risks, and confront 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 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.

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.

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 can 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 are now increasingly recognized as essential members of care teams. Relevant knowledge and best practices offered in accessible ways such as guides written by persons with lived experience for peers, alongside counselling and education by experts, were cited as vital resources for supporting this essential role.

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.

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.

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.

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

To conclude, 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.