Ontario Behavioural Support Systems

A Framework for Care

JANUARY
2011

In this report

The case for action

1. The numbers of people are increasing
2. Challenges are experienced across all health sectors and services
3. The person and family require better quality experiences
4. Significant costs are incurred
5. Best practices could be more systematically adopted
6. Existing initiatives can be leveraged
7. Stakeholders are ready for change

Within our reach: Solutions for improving support for older Ontarians with challenging behaviours

Older people with cognitive impairments due to mental health problems, addictions, dementia, or other neurological conditions often exhibit responsive or challenging behaviours such as aggression, wandering, physical resistance and agitation. These behaviours, which occur whether the person is living at home, in acute care or in long-term care are a major source of distress to the person with the behaviour, family caregivers and others providing support.

We call this behaviour “responsive,” because it is not unpredictable, meaningless aggression or agitation, but is due to circumstances related to the person’s condition or a situation in his or her environment. Although people with responsive behaviours and their caregivers need high levels of support, sadly it is often inadequate or even non-existent. The number of people with cognitive impairment is growing, which places further strain on individuals and the entire healthcare system. **Fortunately, solutions are within our reach.**

The Behavioural Support System Project

In January 2010, the Ontario Ministry of Health and Long-Term Care funded a working group to undertake the first phase of an Ontario Behavioural Support System Project (BSS) and develop a principle-based Framework for Care that would mitigate the strain and improve outcomes for persons with challenging behaviours, families, health providers and the healthcare system.

Alzheimer Society ONTARIO

Alzheimer Knowledge Exchange

Ontario Local Health Integration Network

Methodology

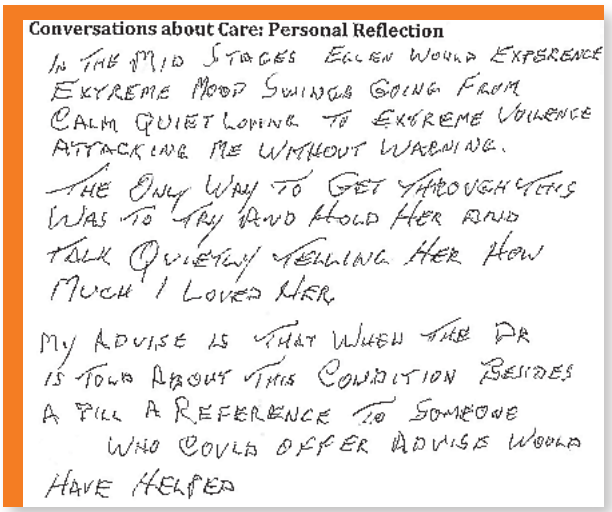
We considered:

- **Lived experience of approximately 100 caregivers**
- **Practice-based knowledge: the Seniors Health Research Transfer Network's (SHRTN) Mental Health Community of Practice regional forums, feedback members of the Virtual Advisory Panel, key informant and opinion leaders interviews**
- **Research-based knowledge: a literature review of relevant research and resources**
- **Health System cost and Utilization Data and an inventory of newly funded services were found to be inadequate in describing system-wide costs associated, e.g. ED and ALC costs, inadequate supports to caregivers.**
- **National Leaders: 3 discussions were held with support from CIHR and Canadian Dementia Research and Knowledge Exchange**

Readiness for change

To develop the Framework, we looked for information and advice. Almost 100 family caregivers who supported people with responsive behaviours participated in Conversations about Care, a series of focus groups led by Dementia Networks and Alzheimer Societies. They provided rich evidence of need and modest and practical suggestions for improved supports[1].

Our process of engagement galvanized people at every point in the healthcare continuum and reoriented many to seek solutions through collaboration. We found a readiness for change. For example, the Seniors Health Research Transfer Network Community of Practice (SHRTN CoP), with Ontario Health Quality Council (OHQC) support, held 11 cross-sectoral meetings for clinicians across the province. These forums had several purposes: develop local partnerships and collaboratives; use a quality improvement approach to address specific improvement challenges; obtain feedback on a strategy to link policy and practice in target LHINs; and support knowledge exchange.


Conversations about Care: Personal Reflection

In the mid stages Eileen would experience extreme mood swings going from calm quiet loving to extreme violence attacking me without warning.

The only way to get through this was to try and hold her and talk quietly telling her how much I loved her.

My advise is that when the Dr is told about this condition besides a pill a reference to someone who could offer advise would have helped.

The case for change is self-evident: we need to transform how we care for this important population. Key stakeholders – family caregivers, professionals in the field, the leaders and staff of Local Health Integration Networks (LHINs) and officials in the Ontario Government - are ready to create better health, care and value for older adults with behavioural challenges and their caregivers. They are ready to build on current programs supporting seniors, to use their quality improvement skills to find the problems and to create innovative, lasting solutions.

Nationally, the issue has also galvanized stakeholders to action. In three meetings in 2010, approximately 45 leaders from each Canadian province and some territories discussed solutions.

The BSS project report reflects the voices of the families and the professionals and those with whom they work.

Framework principles

Person and caregiver-directed care is the overarching principle:

- Everyone is treated with respect and accepted "as one is"
- Person and caregiver/family/social supports are the driving partners in care decisions
- Respect and trust characterize relationships between staff and clients and care providers

Supporting principles bring these concepts to life for those making daily decisions about care:

1. **Behaviour is communication:** Behaviours are an attempt to express distress, solve problems or communicate unmet needs. They can be minimized through interventions based on understanding the person and adapting the environment or care to satisfy the individual's needs.
2. **Diversity**: Practices value the language, ethnicity, race, religion, gender, beliefs/traditions, and life experiences.
3. **Collaborative care:** Accessible, comprehensive assessment/interventions include shared interdisciplinary plans of care that rely on input and direction from the client and family members.
4. **Safety**: A culture of safety and well-being is promoted where older adults and families live and visit and where staff work.
5. **System coordination and integration:** Systems are built upon existing resources and initiatives. Partners to enable access to the range of needed, integrated services and supports.
6. **Accountability and sustainability**: The accountability of the system, health and social service providers and funders to each other is defined and ensured.

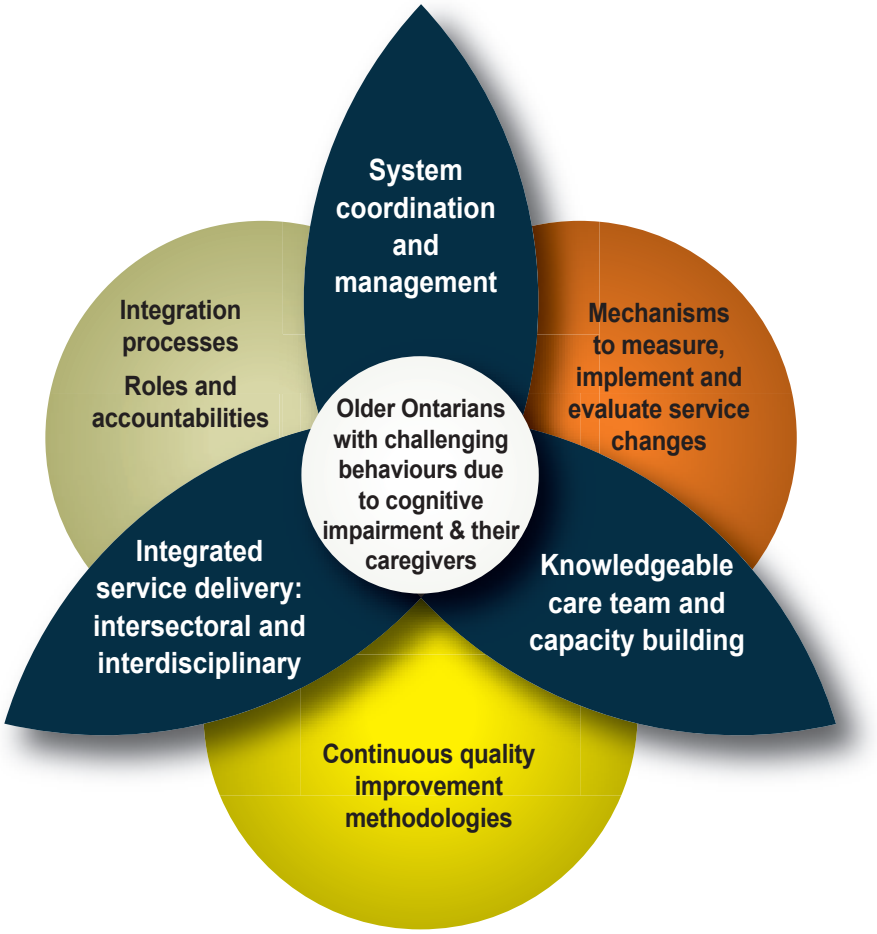
1 Conversations about Care: The Lived Experience, the Ontario Behavioural Support System Project, Aug 2010 BSS Project Appendices www.BSSproject.ca

The Framework for Care

While elements of the Framework exist in many places, their consistent application is rare. The resulting gaps in collaborative transitional services are key impediments to providing needed and quality care.

Simple in design but with great potential to improve care, our model is comprehensive: broad in its inclusion of all points of care and flexible in its application to communities of different sizes. Its key message is also simple: better integration and collaborative transitional services = better care and health outcomes, better value, and lowered risk.

The Framework's three components facilitate continuous improvement.



System coordination and management

Coordinated cross-agency, cross-sectional collaboration and partnerships based on clearly defined roles and processes are required to facilitate seamless care.

- Establish system management through a coordinated network of service providers and regional coordinators with accountability to LHINs
- Initiate integrated, collaborative intake, transitions and referrals.

Integrated service delivery: intersectoral and interdisciplinary

Outreach and cross-sector interdisciplinary transitional teams across the continuum enable equitable and timely access and transitions to the right provider for the right service.

- Introduce collaborative/shared care service delivery through mobile interdisciplinary cross-sector and system support teams, case management and intersectoral frameworks and communication vehicles
- Value the least restrictive and least intrusive approach: enhanced approaches and services that promote early detection and health promotion; specialized residential treatment

What we know

- **The number of Ontarians with dementia will increase by 40% by 2020; in some LHINs it will increase by 42% in half that time**
- **30% of home care clients with dementia exhibit some behavioural symptoms**
- **65% + of long-term care residents have dementia or mental health issues**
- **17% of long term care home residents are physically restrained – a higher rate than in other countries**
- **34% of nurses in hospitals or long-term care facilities in Canada reported physical assault over the past year and 47% reported emotional abuse**
- **Acute care hospitals in Ontario reported that ALC patients occupied 17% of all acute care beds; half were waiting for long-term care; over 36% had moderate to severe cognitive impairment and 19% had exhibited behaviours**

If we fail to act

- **ED, ALC and home care congestion will increase**
- **Haphazard development will continue**
- **System impact will go unmeasured while costs rise**
- **Family caregivers will continue without needed supports**
- **Healthcare providers will serve without adequate training and care protocols**
- **An opportunity to improve the quality of life for a growing number of people will be missed**

The Framework for Care (continued)

Knowledgeable care team and capacity building

Education and training strengthen the capacity of family caregivers and professionals. The goal is person-directed care, prevention and early detection; implementation of standardized best practices in behavioural health; and continuous quality improvement.

- Help families make informed choices
- Create supportive learning infrastructures and foster collaboration between individuals, teams, organizations, systems
- Nurture cutting edge research and apply new technologies
- Support efficient, effective use of human resources and evidence-based decisions.

One Ontario leader recently said, “Good system management equals good seniors care.” Our Framework advances these two goals simultaneously and the evaluation framework will ensure return on investment and positive system impact. Above all, a good experience for people with responsive behaviours will have a beneficial impact on our overall health system.

Moving forward

Our recommended solutions align with Government and LHIN strategies and programs: Excellent Care for All; Healthy Communities/Healthy Seniors; Aging at Home; and Emergency wait times and Alternative Levels of Care reduction. They also support the recommendations of two recent reports: the Respect, Recovery and Resilience report on Mental Health and Addictions and the report of the Select Committee on Mental Health and Addictions. Integrated leadership on these initiatives will enable transformational change at the service level.

Our team will continue to work with the families, the field, the LHINs and the Ministry to:

- Disseminate the results of **Phase One**
- Promote exchange among innovators
- Develop an evaluation with Aging at Home Projects, including impact measures
- Expand the inventory of existing services
- Encourage new developments such as Residents First and Integrated Models of Care initiatives.

By weaving them together, the Framework and its phased implementation plan will strengthen investment decisions currently made individually by several LHINs.

The **OBSS** project team appreciates that the Minister and staff and the Local Health Integration Networks recognize the significance and urgency of the issues. We look forward to working with them to move toward a comprehensive Framework as soon as possible.

The Ontario Behavioural Support Systems Project is a joint initiative of:

Alzheimer Society of Ontario
Alzheimer Knowledge Exchange
Local Health Integration Networks
Supported by the Ontario Ministry of Health and Long-Term Care

www.BSSproject.ca

Throughout its work, the project issued several documents found at www.BSSproject.ca.
Working paper #1 “Behaviour has Meaning” provides greater detail and lists our many contributors.