

Providence
Care
Behavioural
Support
Services

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South East Ontario Lived Experience Network Report 2016-2017

www.dementiacrossroads.ca

“We cannot adequately meet the needs of the people and families we serve,
without asking them first what it is they need” ~Dr. Ken Le Clair~



Introduction:

The Lived Experience Network has continued to grow this year reaching out to older adults and their family/care partners living with dementia, mental health, substance use and/or other neurological disorders. Since the Lived Experience was launched in the fall of 2013, 591 people have been involved in advisory conversations. The fiscal year 2016-2017 saw a continued momentum of lived experience engagement; consultation; and knowledge translation activities. The voice and perspective of lived experience is surfaced through the work of a dedicated Lived Experience Facilitator through face to face conversations; on-line live chats; and telephone or email correspondence. Through this work the information gleaned from these conversations that matter will serve to:

- 1) Inform change within the Behavioural Support System of Care ensuring a person and family centred perspective
- 2) Ensure skills are identified and developed for persons, providers, and programs that enable active, meaningful involvement of the individuals and families in their health and healthcare.
- 3) Provide lived experience feedback and reflections to continue to improve the developments and delivery of the Behavioural Support Initiative on an ongoing basis.

Themes (Recurring and New):

The South East Ontario Lived Experience Network began as a project in 2013-2014 and proved to be an important link between the voice and perspective of the person and their family/care partners living, and the Behavioural Support System of care. Through the 2013-2014 project six themes were identified by the Lived Experience Network and continued to be relevant in 2016-2017 and are as follows:

1. Dignity
2. Consistency in the Care Journey
3. Clear Communication
4. Sufficient Staff and Services
5. Knowledge and Skill
6. Care and Compassion in their health care experiences

Other themes identified as priorities by the Lived Experience Network in 2016-2017:

1. The need for better navigation and coordinated care.
2. The need for the family/caregivers to be better equipped with hands on skills (behavioural approaches, communication, and training to provide personal care) when caring for their loved one at home as well as when they are in long term care.
3. The need for counselling to deal with grief and loss and how to manage the stress they live with on a daily basis.

2016-2017 Activity Metrics

Measure	Definition	Total	Comment
Number of Lived Experience Network Members	Total Number of Lived Experience Network members since the inception in 2013	607	
Number of New Lived Experience Network Members	Total Number of New Lived Experience Network members from April 2016-March 2017	128	
Number of Live Conversations with people with Lived Experience	Total Number of Live Conversations April 2016-2017	247	Includes in person; telephone; and live online chats
Number of Lived Experience Café members	Total number of current Lived Experience Café members	80	Lived Experience Café is the monthly On-Line Chats
Number of Live Chats through Lived Experience Café	Total number of monthly facilitated On-Line chats.	11	No chat in April 2016 due to a pause in the funding
Number of Knowledge Translation Activities	Number of Activities to pass on translated findings and themes from lived experience conversations with the understanding these findings are assisting in shared development or improvement of services-live or virtually	1270	Activities include sharing at/participating in: Workshops; conferences; Behavioural Support Networksx3; Resource Exchange; LTCH requests etc
Number of Knowledge Translation Receivers	Number of people/organizations received the translated findings/themes from lived experience conversations with the understanding these findings are assisting in shared development or improvement	1531	Include PC SMH/BSS teams; Leadership Team; Alzheimer Societies Caregiver workshops; LE Resource Exchange; Behavioural Support Networks; CCAC; Health Links; BSTU; PCH Inpatient Unit; PC AMH Community; LTCHs
Number of Knowledge Exchange Activities	Opportunities/meetings or teaching times where lived experience knowledge and experience of others is shared as education for students; medical students;	15	
Number of Networking Opportunities	Networking opportunities for LE partnership across the Behavioural Support System	61	Includes at various events; invitations to partner ; Alzheimer Societies; Health Links; SE BSSAC
Number of Consultations	Includes LE consultations for Behavioural Support System; design; Quality Improvement where LE input/advice is requested	84	Includes monthly meetings with PC BSS Leadership; BSTU meetings; Health Links; Capacity Enhancement

The Year in Review

2016-2017 proved to be another successful year for the Lived Experience Network facilitated by our Lived Experience Facilitator.

- There was an increase in numbers of contacts as well as advisory conversations.
- Advisory conversations occur across the entire South East region however this year saw a growth in new areas of Napanee; Deseronto; and Gananoque
- There has been a growth in partnering across the SE region:
 - **Long Term Care Behavioural Support Networks:** As well as being part of the *South East Behavioural Support System Advisory Committee* and the *Quinte Health Links Steering Committee*, this year relationships were built regionally with my participation on the newly formed: HPE Long Term Care Behaviour Support Team, The (LTC) Behaviour Support Cooperative of Lanark, Leeds Grenville and The (LTC) Behavioural Support Network of KFL&A. The opportunity to be part of these ongoing meetings has built positive relationships between myself and LTC home staff and has also increased the number of referrals to residents and their families.
 - **Family Council Meetings:** Due to the relationships built with Long Term Care Homes, there was an increase in invitations this year to participate in advisory conversations with Family Councils (as well as Alzheimer Society Support group) meetings.
 - **Lived Experience Resource Exchange:** This year the Lived Experience Resource Exchange grew from an email to 60+ interested partners to being placed on the www.dementiacrossroads.ca website. Bi-monthly updates are placed describing the key findings of all lived experience advisory conversations. The email list of partners (who receive prompts each time it is updated) is over 200 people now.
 - **Dementia Capacity Planning Clinical Advisory:** I was invited by Dr. Dallas Seitz to participate in a short term advisory group (based on my observations of Lived Experience advisors in the South East and Provincially).
 - **Dr. Julia Kirkham - Patient Family Support Mentorship:** I participated as a Patient Family Support Mentor for a research project Dr. Kirkham was part of.
 - **Providence Care Quality Improvement:** This year Nate Tompkins, Quality Improvement Facilitator became part of the leadership team for the lived experience project. We have been able to share information back and forth in a way that informs the work of Providence Care. A Quality Improvement Plan is being developed for the Lived Experience Facilitator/Network
 - **PC Community Addictions and Mental Health:** Lived Experience has made a recent connection with the PC Community Adult Mental Health leadership. Will be connecting with those people who have lived with a serious and persistent mental health issue who are now aging and perhaps moving into LTC.
 - **Provincial Partnership:** In April 2016, the BSO Provincial Coordinating Office in partnership with brainXchange began a Provincial Lived Experience Advisory based on the SE model. The SE Lived Experience Facilitator was hired one day per week. In August 2016, the province trialed a SE Ontario and Ontario-wide live chat event and shortly after began hosting regular bi-monthly provincial live chat conversations on www.dementiacrossroads.ca. Several of our SE Ontario members attend both the South East and the Provincial chats, ensuring the voice/needs of the South East are heard in the planning and development of provincial projects.

Next Steps and Opportunities

From a lens of Quality Improvement, the SE Lived Experience Network has always transformed according to the needs; the requests; and the possibilities to support the Behavioural Support System of Care. Moving forward, the Lived Experience Network will continue to strengthen partnerships across the continuum of Behaviour Support care gathering lived experience stories that will inform at an individual; program; and system level.

New this year and an exciting opportunity! The SE Lived Experience Facilitator has been supported by the BSO Provincial Coordinating Office to become a Teepa Snow trainer (along with 3 other people from the South East Lived Experience Network). The PRCs will support these lived experience people in learning facilitation techniques etc and then they will be able to provide Teepa Snow training to family caregivers. This is an excellent resource in the South East. Since they were funded by the province they have committed to training 1-2x across the province. Next steps: Kathy Baker and Sharon Osvald meeting with ED of the SE Alzheimer Societies to begin planning for this education of informal caregivers. This will meet a need identified (#2) in the 2016-2017 Lived Experience priorities. In addition, the MRT and SMH Outreach teams will be trained in the Teepa Snow techniques (positive approach to care). The PRCs will bring this training to LTCHs and if available will partner with the Lived Experience trainers

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“Honouring people, possibilities, and partnerships”

~Behavioural Support Services Sept 2013~

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in partnership with the Alzheimer Societies of S.E. Ontario &

BSO Provincial Coordinating Office in partnership with brainXchange

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