



## Behavioural Supports Ontario Provincial Lived Experience Network Meeting

### Meeting Information

Date: Thursday, May 19, 2016

Time: 12:30pm – 2:00pm (EST)

	Agenda Item & Description	Time	Information	Discussion	Decision/Approval	Lead
-1-	<b>Welcome &amp; Introductions</b>	15 min.	x			Monica Bretzlaff Sharon Osvald
-2-	<b>Lived Experience Café Overview &amp; Upcoming Events</b>	20 min.	X			Sharon Osvald
-3-	<b>Environmental Scan of Lived Experience Groups</b> - Sharon and PCO team members have collected work is happening across the province regarding Lived Experience - ODAG (Ontario Dementia...) -Kathy Hickman (knowledge broker from brainXchange) working with ODAG ... - Alz Society of Ontario Inclusion Task Force – to - Various groups occurring locally (e.g. Waterloo Wellington Dementia Advisory Groups) - Dementia Friendly Communities - Schlegal Village Dementia Advisory Committee connected with a Research Institute - Homewood - Phyllis sends any of her research to the Schlegal Village - world wide dementia advisory	20 min.	x	x		Sharon Osvald

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	<ul style="list-style-type: none"> <li>- HQO – working on pt engagement</li> <li>BSO not wanting to reinvent the wheel, but build on work that is already happening. Want to reach out to create partnerships.</li> </ul>					
-4-	<p><b>Review of Lived Experience Network Priorities Survey Results</b></p> <ul style="list-style-type: none"> <li>- survey was to get an idea of who is in the network and what projects we should be working on</li> <li>- 9 received so far</li> <li>- plan for survey to be left open longer so that others can complete</li> <li>- INSERT results</li> <li>- the live chats was prior to this meeting where the chat info was discussed</li> <li>- projects – pulled from past meetings and Catalyst event – listed all these projects</li> <li>- so far the following were prioritized:</li> </ul> <ol style="list-style-type: none"> <li>1) Identify education needs among family care partners caring for those living with mental illness, dementia, substance use and/or neurological disorders and determine potential strategies to increase learning opportunities.</li> <li>2) Develop and promote the use of a tool for health care professionals to increase knowledge about BSO patients' personhoods (e.g., likes/dislikes, greatest accomplishments, fears, etc.) - similar to 'All about Me', 'My Plan', etc.</li> <li>3) Project/plan to promote BSO Minisites (<a href="http://behaviouralsupportsontario.ca/">http://behaviouralsupportsontario.ca/</a>) to increase knowledge among the general public about the availability of behavioural support services through BSO across the province</li> </ol> <p><b>suggested other projects:</b></p> <ul style="list-style-type: none"> <li>- send out a PR or targeted to media ..</li> <li>- increased knowledge of where to find help</li> </ul>	<p>10 min.</p> <p>20 min.</p>	<p>x</p>	<p>x</p>	<p>x</p>	<p>Sharon Osvald Katelynn Viau</p>

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	<p>- look at a way to disseminate research to real life</p> <p><b>Follow-up Discussion</b>  Identify education needs among family care partners caring for those living with mental illness, dementia, substance use and/or neurological disorders and determine potential strategies to increase learning opportunities.</p> <ul style="list-style-type: none"> <li>- more than one way to get out there</li> <li>- it was like being called in a cold ocean – “go to the Alz Society” – we needed some direction and navigation tool</li> <li>- info was about stages and types of dementia – not practical</li> <li>- not talking about the practical day to day (e.g. this is what to expect, who to call)</li> <li>- this type of tool might be already available locally, could there be a provincial tool</li> <li>- First start with “what are the things you wished you knew?”</li> <li>- Resource needed available on-line and in print “what do I do now?”</li> <li>- Challenges to navigate the application into LTC, integration into LTC,</li> <li>- Interaction with people that can provide support</li> <li>- Many people don’t want to attend support groups (a club that no one wants to join) – need to find a way to get these info to them</li> <li>- Finding ways to help people that they want/need to a level that they want.</li> <li>- LTC – Could family councils be a</li> </ul>					

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	<p>resource for support and information?            Family councils are a very fragile thing – at times it is strong and at times not, at times the focus is only on advocacy (not support). At times there may not even be a council.</p> <ul style="list-style-type: none"> <li>- Family Council of Ontario – new developed as a stand alone organization</li> <li>- New LTC Home Act – if there is interest shown then the home has 30 days to get a family council operational</li> <li>- Chat topic – “What do we wish we knew?” and “Where would we find this information?/ Where do we look?” so the tool could be placed there</li> <li>- A pamphlet/guide/tool – doesn’t need to be all encompassing</li> <li>- Suggest posting this on various places where it can be accessed (e.g. websites of partners, primary care providers)</li> <li>- Local services vary across the province – how do we deal with this in a provincial brochure/guide – point to the Minisites</li> </ul> <p>3 Sections (include journey between these 3 periods):</p> <ol style="list-style-type: none"> <li>1. Caregiving at home</li> <li>2. Process of going to LTC (application)</li> <li>3. Admission to LTC (changing role as a care giver)</li> </ol> <p>(include educational opportunities)</p> <p>Phyllis – interest in quality indicators</p> <ul style="list-style-type: none"> <li>- important to look at the positive</li> <li>- negative headlines is demoralizing for those that work in LTC and creates fear in the public</li> <li>- what led the family to use the words</li> </ul>					

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	<p>Receiving Educational opportunities – liked to be provided these opportunities, want to know about them and they can decide if they want to sign up</p> <ul style="list-style-type: none"> <li>- add these opportunities from on the dementia crossroads website (online and in person)</li> </ul> <p>2) Develop and promote the use of a tool for health care professionals to increase knowledge about BSO patients' personhoods (e.g., likes/dislikes, greatest accomplishments, fears, etc.) - similar to 'All about Me', 'My Plan', etc.</p> <ul style="list-style-type: none"> <li>- Alzheimer's Socitey one – becomes a chore (e.g. 40 pgs), caregivers have a hard time reading a long document</li> <li>- need to be streamlined (not so long)</li> <li>- NE one pager – gain permission to post in the room</li> <li>- a wife wrote up a one page about her husband to help staff know about her husband.</li> <li>- people might now realize my this information is so valuable</li> <li>- this information is very helpful with regards to responsive behaviours</li> <li>- how would we encourage LTC to use? - PRCs help?</li> <li>- What tools are being used? Do a scan regarding these tools</li> <li>- things are always changing in terms of the strategies that work – communication is not flowing with these strategies</li> <li>- a tool that needs to go with the person if they move throughout the health care system</li> <li>- privacy of personal information – need to consider how this information is shared in line with legislation (e.g. SDM to provide consent for this sharing/posting of information).</li> </ul>					

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-5-	<p><b>Review of Next Steps &amp; Conclusion</b></p> <ul style="list-style-type: none"> <li>- pick a consistent time for Advisory mtg bimonthly (e.g. third Thursday of month (1230 - 1400)</li> <li>- meeting in July – people away, but it is too much time to wait until Sept so plan to keep July mtg</li> <li>- suggest to send a pole regarding the best day of the week</li> <li>- the hope that providing notice will be helpful so that everyone has it in their calendar</li> <li>- Next live chat – third Wed of month (in evening)</li> </ul> <p>PCO will send out:</p> <ul style="list-style-type: none"> <li>- link to dementia crossroads</li> <li>- personhood documents</li> <li>- meeting notes</li> </ul> <p>TOR differed – still need to discuss, looking for survey to direct</p>	5 min.	<b>X</b>		<b>X</b>	Sharon Osvald