



Catalyst Initiative: Ontario's Best Practice Exchange

Engaging the Lived Experience

Guidelines for the inclusion of older adults with dementia, mental health, substance use and/or neurological disorders and their informal care partners in your collaborative

Introduction

In order to promote the development of best practices in each of our seven collaborative areas, it is an expectation that each collaborative will engage with and include at least one to two persons with lived experience in their group (see '**Defining the Lived Experience**'). The following document developed by the *Person & Family Centred Care* Collaborative will help guide your team in the planning and engagement of these individuals.¹

Why Involve those with Lived Experience?

Increasingly, people with lived experience are being invited to take part in conferences and events such as ours. This is a great way to ensure that people with lived experience have meaningful opportunities to influence activities that affect them and that the initiatives we are developing are informed by the real needs of those who they are intended to impact. The needs of persons with lived experience can only be met by truly listening to and including their voices in the development of our best practices and our overall decision-making.

Defining the Lived Experience

Lived Experience refers to the experience of living with dementia, mental health, substance use and/or neurological disorders or the experience of being a care partner of an individual with these conditions. Examples of care partners may include family members, friends, etc., who play or played an active role in supporting an individual living with the above conditions emotionally and/or physically.

Inviting someone with Lived Experience to join your Collaborative

Contributing to one of our seven collaboratives can be done in the form of participating as a collaborative member, sharing ideas and opinions at planning meetings, participating in leading a workshop at the September event and/or contributing to/consulting on ideas as conference participants. No matter how you think it best or how individuals want to be engaged, realize that this experience may be something entirely new to them and to others in the group. As such, it is imperative to be very clear with what your goals and objectives are:



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- 1. BE CLEAR ABOUT YOUR EXPECTATIONS-** Are those with lived experience expected to attend upcoming meetings? What is the commitment? Are they being asked to give a formal presentation? How long of a presentation is needed?
- 2. ENSURE THAT THERE IS ENOUGH PLANNING TIME BEFORE THE EVENT-** Ensure plenty of time for preparation. It is possible that people with lived experience may need more time to review meeting materials, process information and participate in discussions. Send needed materials well in advance of meetings and events and be prepared to slow down the conversation so that everyone has an opportunity to participate. Taking the time to truly understand the experience will lead to better results.
- 3. MAKE SURE THERE IS SUPPORT FOR THE PERSON TO ATTEND-** Ask individuals with lived experience what supports would help them to be involved. Would having one person be the contact help? Do they need assistance with travel? Would they prefer to join one or more collaborative members in person rather than participate in teleconferences on their own? Would they like to bring a companion or care partner along or as a care partner, does respite care need to be arranged? Would reminder calls or a phone conversation before or after meetings be helpful? Being clear about the support that can be offered and where it will come from is essential.
- 4. KEEP IN TOUCH-** Check in regularly with members with lived experience to make sure the process is working for them. What else they might need to make it work better?
- 5. HAVE A CONTINGENCY PLAN-** For facilitation of your session at the conference, it is possible that individuals with lived experience may suddenly not be available on the day of the event. Consider how you will ensure that lived experience stays central to your session. For example, think about having someone else fill their role on their behalf or show a film that accurately depicts the lived experience instead.

Using Person and Family-Centered Inclusive Terminology

A person and family centred approach to the language and terms used throughout your planning meetings and during the event is essential to the successful engagement of the lived experience. Choose inclusive, everyday language that is accessible to everyone whether they are familiar with language used in the health care sector or not. Give some thought surrounding the language and terms used to describe the lived experience that is specific to your collaborative.

- Do not use words which objectify or depersonalize individuals (e.g. dementia sufferer, demented)
- **INSTEAD**, use alternative phrases such as “person with mental illness” or “living with bi-polar disorder”
- Avoid the use of terms that are dated (e.g. senile dementia)

Note: Some of the ideas you wish to share in other presentations may be upsetting to people with lived experience. This doesn't mean that you shouldn't include it; however, consider the ways in which these ideas are presented.



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Financial Support for Participants with Lived Experience

The Alzheimer Society of Ontario has provided financial support to the Best Practice Catalyst initiative to ensure the inclusion of lived experience. When inviting participants to take part in the planning process or September 25th event, work with them to identify what financial barriers might prevent them from participating, then identify the costs and share these with your collaborative's Knowledge Broker via the Financial Assistance Information and Request form for approval.

Essentially, any cost that would prevent participation of people with lived experience is eligible; listed below are some examples of expenses that could be covered:

- Travel costs to attend the event or planning meetings
- Accommodation the night before or after the event to allow participants to be well-rested
- Meals outside of those offered at the event (breakfast, lunch and snacks [Sept. 25]).
- Travel and accommodation costs for a companion to attend the event
- Respite care costs to allow a care partner to participate
- Costs for child or pet care so that the person with lived experience can participate

ⁱ Guidelines are based on the 'A Changing Melody: Creating Partnerships in Dementia Care' Toolkit (Dupuis, Gillies, Mantle, Loiselle & Sadler, 2008) and the 'DEEP Guidelines for Involving People with Dementia in Conferences and Events' available at <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Conferences-and-events.pdf>