



November 11th, 2016

To Whom It May Concern:

I am writing this letter on behalf of the members of the Ontario Dementia Advisory Group (ODAG), to share our support for Laura Booi's application for the 2017 Alzheimer Society Research Program's Post-Doctoral Award. Laura's proposed study *exploring the use of social technologies to maintain social inclusion in the lives of individuals living with dementia* is both important and timely for those currently living with dementia and those who support people living with dementia.

ODAG is a group of active Canadians who are currently living with dementia. The majority of our members live in Ontario but we have members throughout the majority of Canada. Our mandate is to influence policies, practices and people to ensure that we, people living with dementia, are included in making decisions that affect our lives. We firmly believe that all persons with dementia, regardless of age, stage, or place of residence, have a fundamental right to help define and feel included in their communities. According to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), an international treaty, Article 3 specifically references the right for participation, inclusion and opportunity on an equal basis of non-disabled people.

We believe in three key principles which guide our work:

- 1) We are the experts
- 2) Working WITH and not for
- 3) Nothing about us without us

As people living with dementia, we have personal perspectives about dementia that no one else has. We recognize that the involvement of people living with dementia has lagged behind other groups because there are often assumptions that people living with dementia are unable to communicate their needs, wants, and perspectives with others. This has led to social exclusion, and this is something we find unacceptable. This is also why we have taken action to support Laura's proposal for exploring the use of social technologies- specifically Zoom technology, in the use of facilitating social engagement in those living with dementia.

Zoom technology is the international choice for people with dementia. Therefore, Laura is assured access to our members regarding asking for their participation in semi-

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structured interviews both in-person and virtually using Zoom technology. Laura is also assured access to request interviews with our members' family care-partners. By using Zoom technology Laura will be able to interview individuals living with dementia who researchers would otherwise not have access to. Zoom allows for those living with dementia, who do not have the capacity or means to travel, to still have their voices heard and valued.

There are many reasons Zoom is the technology of choice for people with dementia, which include but are not limited to the following:

- ease of use
- ability to use just phone, video or both
- ability to have break-out rooms
- ability to have live polling questions
- ability for report generations
- excellent and quick product support, and the
- ability to save recordings to a local drive.

ODAG is well-versed at helping researchers conduct participatory research with those living with dementia. Our members have worked with various dementia research teams including Waterloo University's Murray Alzheimer Research and Education Program (MAREP); the Ontario Brain Institute; Dr. Kathy McGilton Senior Scientist, Toronto Rehabilitation Institute, Dr. Mariette Brennan, Assistant Professor, Bora Laskin Faculty of Law, Lakehead University, and others.

ODAG will also support Laura in the creation of her Dementia Advisory Group. In this role it is understood that Laura will work with the newly created Dementia Advisory Group to co-create her interview guide, research questions and ultimately, the proposed training module that will be used to facilitate social engagement in those living with dementia through the use of social technologies, specifically Zoom technology.

Please do not hesitate to contact me if I may provide any further information in support of Laura's proposed application for the 2017 ASRP/AGE-WELL Post-Doctoral Award.

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Sincerely,

A handwritten signature in cursive script, appearing to read "M. Wighton".

Mary Beth Wighton
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www.odag.ca

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