



September 20th, 2016

Dr. Elaine Wiersma  
Director, Centre for Education and Research on Aging & Health  
Associate Professor, Department of Health Sciences  
Lakehead University  
955 Oliver Rd.  
Thunder Bay, ON P7B 5E1

Dear Dr. Elaine Wiersma:

I am writing this letter on behalf of the members of the Ontario Dementia Advisory Group (ODAG), to share our support for your proposed **CIHR – Operating Grant** research project: **Practicing Citizenship: Supporting people with dementia in leadership roles.**

As you know, ODAG is a group of Ontarians living with dementia. 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. In addition, we firmly believe all persons with dementia need to be able to influence as this is the only way that we will create a system that is responsive to the needs and desires of people with dementia. Furthermore, this is in accordance 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.

For far too long, care partners have been the "proxy" for people with dementia, and it's time for us to speak up and engage in leadership activities. However, there is a lack of leaders necessary to push for change and drive activities with and for people with dementia. It has been communicated loud and clear from people and groups all over the world that we need a coaching and/or mentorship program developed for and by people with dementia.

ODAG is in the unique position that we are able to be an integral part of the research team, as evidenced that we are included on the grant application as knowledge users, and that we are involved in all aspects of the research grant.

ODAG is considered to be a leader in the international world of advocacy. We have provided witness for the Canadian Standing Senate Committee on Social Affairs, Science and Technology for its study on dementia in Canadian society. ODAG used the United Nations on Convention on the Rights of Persons with Disabilities (UN CRPD) accessibility article to obtain a number of accommodations from the government. Also, we are a member of new Task Force submitting a Memorandum to the UN CRPD as it relates to "Concluding Observations" report from the UN to Canada.

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We are delighted to share our experience and expertise as leaders who have made significant change in a mere two years. To that, we are willing to pilot the coaching/mentorship program for people with dementia and to work with organizations to help them understand what they need to do to support people with dementia, including Alzheimer Societies as needed to ensure that these programs are implemented and supported.

This proposed project will surely have a substantial impact on improving the quality of life of people with dementia. We welcome the opportunity to share our experiences and perspectives with you and your team and will be pleased to collaborate in and advise on different aspects of your research.

Please contact me if you have any questions.

Sincerely,

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

Mary Beth Wighton  
Chairperson - Ontario Dementia Advisory Group (ODAG)  
[www.odag.ca](http://www.odag.ca)