

Ontario Dementia Advisory Group

Meeting Minutes

April 9, 2015

1:00 p.m. – 3:00 p.m.

Present: Nancy, Bea, Gina, Delia, Lisa, Mary Beth, Bill, Elaine

Regrets: Maisie, Phil

Nancy Rushford	Program Director at the Alzheimer Society of Ontario
Maisie Jackson	Connected with the Alzheimer Society of Niagara
Bea Kraavenhof	Connected with the Alzheimer Society of Niagara
Gina Bendo	Alzheimer Society of Niagara
Delia Sinclair	Alzheimer Society of Ontario, Public Policy and Advocacy
Phil Caffery	Alzheimer Society of Ontario, Public Policy and Programs
Lisa Loiselle	MAREP, University of Waterloo
Brenda Hounam	Paris, Ontario, spokesperson and advocate
Mary Beth Wighton	Southampton, advocate, FTD
Bill Heibein	Advocate and spokesperson
Elaine Wiersma	CERAH, Lakehead University

1. Reviewed meeting minutes from March 23rd, 2015

- There were no questions about the notes from the previous meeting.

2. Updates

- Al is still interested in being part of the group, but he cannot participate at this moment as he is going for surgery and needs time to recover.
- Mary Beth has written the thank you letter to the speakers that donated money to ODAG at Passport Day. Delia will get the speakers' email address and forward them to Mary Beth.
- Delia requested to get some reflections from Indira about the meeting, but she has not heard back.
- Nancy will request a summary report from the interview with Idea Couture.

a. Update on government activity (refer to document created by Delia, titled “Update for ODAG Meeting – 9 April 2015)

- The government was supportive of ODAG’s decision to have rotating representatives on the panel.
- They have not yet worked out the details regarding time commitment, how we would connect to the meetings, and the supports needed by our members as they are still deciding on the structure of the expert group.
- Indira and the minister of Health are deciding between two formats for the expert group:
 1. An Expert Panel that works independently from the government and provides a report with recommendations to the government.
 2. An Expert Advisory group that works closely with Indira and the staff as well as with regional working groups to provide ongoing advice.
- It seems that the government is leaning towards option 2 – the expert advisory group. This is the preferred option as it promotes the involvement of a broad group of stakeholders in the actual development of the strategy.
- Also, with option 1 – the expert panel, the recommendations are not binding and are often not picked up.

3. Discussion around ODAG’s values and membership:

a. Define our vision, goals and objectives

- We need to clearly define our vision, goals and objectives so that we know what we need to accomplish.
- We will get a lot of requests from people so we need a reference point to decide if we should tackle a project or not.
- It will help determine our priorities and what we should spend our time on.
- Mary Beth suggested that our vision should be “People living with dementia in Ontario will be directly involved as experts and at the center of our own care”.
- As everyone shares their ideas and thoughts, Delia will record all the points on the document.
- It was suggested to look at the Engagement document and adapt key points from it.
- We can also take parts from the information on the ODAG website.
- The section “Who we are” was added before “Our Vision” and it states that we are “People living with dementia advocating for people with dementia”
- In “Our Vision”, we should mention something about influencing policies as well as practices and people.
- The following are points suggested for “Goals”:
 - being involved in the development and implementation of public policy that will affect people living with dementia across Ontario

- mentoring others in how to encourage and aid the development of skills that support in the engagement of people with dementia in a meaningful way
- The following are points suggested for “Objectives”:
 - to inspire, encourage and assist people with dementia to be actively engaged
 - ensure our views and perspectives are heard and not overwhelmed by care partners and others
 - increase awareness that there is a benefit to doing the collective approach
 - use examples to show how powerful collective engagement
 - build a network of people with dementia in Ontario through regional/local groups
- Anything on this document should go up on the website as well so that when people go on the website, it can help them identify what we are doing.
- Delia and Mary Beth will work on summarizing all the points and standardizing the wording and we can review it at our next meeting.

b. Discussion around the policy for non-voting, former, active and new members

- For people who have removed themselves from the team, should their name still be listed as a member of ODAG?
- It was agreed that a previous active member that decides to step down from the group due to circumstances beyond their control should be kept in the loop and receive information from the group. However, they will be a non-voting member.
- It was also decided that an asterisk should be placed beside the names of the founding members and members that leave the group will be placed under “former members”.
- We really need to set guidelines for dealing with new members, members that leave, and other membership situations that may arise.
- The vision, goals and objectives is just the start and from there, the group can move into ironing out the process of communication
- Gina mentioned that MAREP’s Partnership Agreement works really well with her group. The document lists things that MAREP and their partners agree to do while working together. It also states what to do if conflict occurs.
- We can use MAREP’s Partnership Agreement as a foundation. Gina will send this document to everyone.
- We also need to decide what to do when the guidelines don’t work.
- It is important to understand our vision, goals and objectives first. Once we all agree with this, we can then set the framework and figure out what’s next.
- We will discuss this further at our next meeting.

c. Discussion around the 6th spot – reserved for First Nations person?

- As a group, we agreed to have diversity in the group, First Nations people should be part of this.
- Currently, there is also work being done regarding First Nations people living with dementia.
- Each LHIN has representation from this population so perhaps we can contact them to nominate someone for the 6th spot.
- We can work with LHIN members or Alzheimer Society chapters that have connections with the First Nations group.
- Trying to get representation from this population presents a political challenge. Instead, we should encourage inclusion of First Nations people within the regional groups. We don't want the person to feel that they are a token representative on ODAG.

5. Review the LHIN map and discuss a communication strategy to encourage people with dementia to get involved

- We need to make sure that every LHIN sees dementia as a priority since they decide where the funding goes in the community.
- Delia can find the scan that identifies which LHINs have dementia as a priority and will circulate this for the next meeting.

6. Discussion around the 'Ethical Framework' for engaging people with dementia in Alzheimer Societies

- Postponed till the next meeting or when we receive more information about this. Bill and Nancy will work on getting more information.

7. ODAG Website

- The profiles of the members are up, if there is anything wrong please let Elaine know.
- Should the website mention ODAG's partnerships? If so, where would you want to display this information?
- Elaine will put up the final version of the engagement document.
- There were 4 or 5 requests that came in through the form. How do you want to respond?
 - There was an individual wanting to volunteer and support the group. Elaine will direct them to the Alzheimer Society.
- Everyone agreed that Elaine can respond to the requests on behalf of the group.

a. Status of our groups personal calendar and password-protected page.

- Elaine/Lisa will work on putting the password-protected page up and uploading all the documents onto this page. The calendar will also be created on this page to put our meetings, event and etc.

b. Distinguish which items should go under the “Our Work” and the “News and Event” page.

- Product that the group has worked on should go under the “Our Work” page such as the Engagement document.
- The content of the “Our Work” page is specific to products and tools that ODAG created.
- Should this be a history of our work or what we are currently doing? It could be both as we could have multiple headings under this page as well.
- “Our Work” should display things that help achieve our vision. Therefore, once we finalize our vision, we can then figure out how to distinguish between these two pages.

Action Items:

- Delia will get the Passport day speakers’ email address and forward them to Mary Beth.
- Nancy will request a summary report from the interview with Idea Couture.
- Delia and Mary Beth will work on writing our vision, goals and objectives to be reviewed at our next meeting.
- Gina will send MAREP’s Partnership Agreement document to everyone.
- Delia will find the scan that identifies which LHINs have dementia as a priority and circulate this for the next meeting.
- Bill and Nancy will work on getting more information regarding the ‘Ethical Framework’.
- Elaine will put up the final version of the engagement document on the website.
- Elaine will respond to those requests on behalf of the group.
- Elaine and Lisa will work on putting the password-protected page and calendar up on the website.
- Everyone send comments to Elaine regarding the website and the profiles, if you have any.
- Delia will figure out the on-going cost of the teleconference line for ASO.
- Elaine will look into using video conference through Contact North.

Next meeting:

Monday April 20th, 2015

1:00 pm – 3:00 pm