

Ontario Dementia Advisory Group

Meeting Minutes

Monday March 23, 2015

11:00 a.m. – 1:00 p.m.

Present: Nancy, Maisie, Bea, Gina, Delia, Phil, Lisa, Mary Beth, Bill

Regrets: Elaine, Brenda

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| 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 2nd, 2015

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

2. Updates

- Brenda expressed to Lisa and Bea that if there is a time when she is available, she would love to attend the meetings so we should keep her in the loop. However, she feels that she shouldn't be voting on anything since she will not be participating on a regular basis.
- Lisa sent the engagement document to those who expressed interest at Passport Day.
- We need to show our appreciation to the speakers at Passport Day that donated money to ODAG. Mary Beth will send them a thank you letter using our letterhead. Delia will provide Mary Beth with the contact information of the speakers.

- Today, the engagement document is also going out to all the local Alzheimer Societies in Ontario.
- Delia has the contact information for all the existing regional groups discovered from the survey and she will send them the engagement document today as well.
- Mary Beth will share the document with the Alzheimer Society of Grey-Bruce.
- We need to check with Elaine if the password protected page on the website and the form have been created. For now, everyone should keep a record of who they are sending our documents to.
- The article featuring Bill and Lisa is up on the ODAG website now. Lisa will circulate the link to everyone.
- Delia is working on getting some reflections from Indira about the meeting.

2a. Update on meeting with Idea Couture

- Maisie said that it was a good experience.
- Idea Couture really appreciated learning about the group and the work we're doing.
- Phil and Nancy will request a summary report of the interview.
- Gina wrote down some direct quotes from Bill, Bea and Maisie during the interview. She will send this out to everyone so that we can see some of the themes discussed.

2b. Update on government activity (refer to document created by Delia, titled "Update for ODAG Meeting- 23 March 2015)

- From now on, before each meeting, Delia will send out an update regarding the activities done by government since our previous meeting.
- These updates will make it easier for us to keep track of the government's progress. We can put the updates on the password protected page on the site.
- Roughly every 2 weeks, ASO will meet with staff from the Health System Transformation division of the Ministry of Health to receive updates and provide feedback related to the Ontario Dementia Strategy and government activity.
- The good news is that the government is finally on board with taking more time to properly carry out the comprehensive engagement process. Originally, the engagement period was set for 6 months, but now it will be for 18 – 24 months with a multiphase approach.
- They are currently making a tour plan to identify who they will connect with, where they will connect with these individuals, and what format will they use to connect with these individuals.
- The initial engagement process projected to start at the end of April will include:
 - An expert panel composed of 15 people with lived experience or professional experience of dementia – ODAG has two spots on this panel.

- Regional roundtables for people with lived experience and professional experience of dementia. 5-6 hours sessions to collect in-depth information.
- Regional town halls – typically an open session hosted for the public.
- ASO will also send 6 questions to the 11 identified local working/advisory groups to gain valuable information from people with lived experience.
- They decided to use the Dutch model where engagement informs initial development and then learnings inform next phases.
- Within the expert panel, there will be 2 people with dementia from ODAG, 1 caregiver and the rest will be professionals from across all health and social sectors.
- There was a concern about people who have no business being there (i.e. sales representatives) having a spot on the panel. However, it was reassured that those people in the panel have lived or professional experience of dementia.
- There was also a concern about the rest of the people having a more dominant voice than the people with dementia during the discussions. However, as long as those with dementia get the questions, the profiles of the people in the panel and other necessary materials beforehand, then it shouldn't be an issue,
- It was brought up that people with dementia should have been involved in picking the 15 panelist. It was explained that the Minister of Health decided this, but ASO does have some influence on this matter as they can provide their opinion to make sure all decisions are representative of the people with dementia.
- Since we have two spots on the panel, we can either:
 - a. Submit the names of two individuals so the same two people will participate each time, OR
 - b. Alternate the two people each time so all the members gets a chance to participate. Names do not have to be submitted, but whoever is taking part of the panel will be representing the group's voice.
- It was decided that ODAG will be sticking with a collective voice and have different members sitting at the expert panel depending on everyone's availability.
- However, we need to be careful and keep in mind the continuity, and understanding of the information discussed at each meeting. We need to ensure that each time we rotate, the members participating should have a good understanding prior to the meeting. It would be hard for someone to step in cold.
- Would we be able to have a support person there to take notes? Would it be possible for everyone to observe while only 2 people are speaking? What are the options available for connecting remotely?
- Delia will share with them our decision regarding the two spots and all our questions/concerns, and give us an update at our next meeting.

- Since Delia is providing us with updates on government activity, would it be okay if she provided them with updates on ODAG's activities? Everyone agreed that this would be okay.

3. Discussion around an interested member who isn't able to connect to a local working group.

- Al Burrige is connected with the Alzheimer Society of Oxford and has been a dementia champion for 5 years.
- Bill knows him as he is also a member of the Alzheimer Society of Canada advisory group.
- We need to have a discussion on how to bring people into the group. Previously, it was decided that there should be 7 members and since things are moving forward with the government, we should look into filling these spots.
- Since Brenda stepped off the committee, currently, we only have 4 members. Al could be the 5th member and we would still have two spots remaining for people representative of the minority.
- Everyone agreed to invite him to come to our next meeting so that he can test the waters, and then decide if he would like to be involved. Delia will invite him to the next meeting and provide him with the minutes.

4. Review the communication process visual document, chart of existing group and ODAG communication map.

- While looking at the chart of existing groups, it is evident that there is a lack of regional representation. Out of 32 Alzheimer Society chapters in Ontario, only 11 are connected with a regional advisory group.
- It is also evident that more people living with dementia need to get involved as only 4 out of the 11 groups are solely made up of people with dementia.
- This chart provides us with a great deal of information. It allows us to see what's there and what's not so that we can identify what changes need to be made.
- It is important to note that there may be other existing groups that have not been identified since they may not be working with their local Alzheimer Society.
- Our challenge is trying to figure out how we can reach people with dementia. How do we connect with people in Ontario in order to provide a true provincial plan? How would ASO move forward in trying to influence local chapters to create an advisory group within their region?
- It was suggested that we should develop a video that can be used as a tool to encourage people with dementia to get involved and create an advisory group in their region. The video can show how those of us who are living with dementia are being empowered to do something.
- The great thing about this idea is that the video speaks to promote wellness, participation and continued involvement within the community.

- Elaine is making a video to profile the regional group in Thunder Bay. Bill was filmed already. For our video, we can possibly work off of what Elaine is creating, we just need to check in with her.
- Instead of encouraging people with dementia to create a regional advisory group within the catchment area of each Alzheimer Society chapter in Ontario, we should look at the Local Health Integration Network (LHIN) map. We should have 14 regional groups that function according to the 14 LHIN areas.
- The government understands LHIN boundaries and the Alzheimer Societies within each LHIN already work together.
- We are not suggesting that the existing local groups should repurpose their group or change their vision. We still want information from them at the local level.
- We just want to encourage the existing groups within the LHIN areas to work together and gather information at a regional level. This information will then be shared with us at the provincial level.
- It would be a good idea to talk to brainXchange about having a webinar about our group and to encourage people to create regional groups within the LHIN areas.
- Nancy and Mary Beth will work on revising the chart of existing groups to correspond with the LHIN areas. We can review this at our next meeting, and identify the gaps and figure out our next steps for encouraging more regional groups.

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

- This discussion was tabled to the next meeting.
- Bill will get more information about this as the Alzheimer Society of Canada advisory group is meeting on Monday, March 30th.

Action Items:

- Mary Beth will send a thank you letter to the speakers that donated money to ODAG at Passport Day.
- Delia will send the engagement document to the 11 existing advisory groups.
- Mary Beth will share the document with the Alzheimer Society of Grey-Bruce.
- Lisa will send everyone the link to the article in the farming magazine.
- Delia is working on getting some reflection from Indira about the meeting.
- Phil and Nancy will request a summary report of the interview with Idea Couture.
- Gina will send everyone a brief summary of the key points Bill, Bea and Maisie shared during the interview with Idea Couture.
- Delia will share with the government our decision regarding the two spots on the panel and all our questions/concerns.
- Delia will invite Al Burrige to the next meeting.

- Nancy and Mary Beth will work on revising the chart of existing groups to correspond with the LHIN areas.
- Bill will get more information regarding the Alzheimer Society of Canada's "Ethical Framework" for engaging people with dementia.
- Delia will look into booking the teleconference line at ASO.

Next meeting:

Thursday, April 9th, 2015

1:00 pm – 3:00 pm