

## Ontario Dementia Advisory Group

### Meeting Minutes

Wednesday February 18, 2015

10:00 a.m. – 12:00 p.m.

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

Regrets: Nancy

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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

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#### 1. Reviewed meeting minutes from February 9<sup>th</sup>, 2015

- Delia will request to get some reflections from Indira about the meeting
- The local CBC in Thunder Bay will speak with Elaine on Friday. Elaine will suggest for them to interview Bill.

#### 2. Brenda's update on Passport Day in Waterloo-Wellington

- David Harvey drafted some speaking notes for Brenda. During the day of the presentation, she had a hard copy of the notes and was able to make her own revisions. The notes really helped her, and made her feel relaxed during her presentation.
- Lisa typed out what was presented, which is available for the group for reference. Notes from presentations like this should be kept on file so that we can draw on them for future use. It would be very beneficial if we could compile notes from

previous presentations and revise them accordingly for future talks, especially when we are given limited time frames to prepare.

- Indira was also present at the event and Brenda was lucky enough to sit at the same table as her. She was quite pleased to see a familiar face.
- As for Indira's presentation, Brenda noticed that she already adjusted her wording. She used "carepartners" instead of "caregivers", and she did not use "suffering" at all. Brenda really appreciated this and expressed to Indira that the rest of ODAG would too.
- Brenda was very thankful that Lisa was there as her support person. Lisa was able to handle all the questions.
- There were lots of inquiries about the engagement document, many wanted to see it.
- Since there was a genuine interest for this document, we need to make some minor revisions and make it our permanent engagement document so we can share it with others.
- People were also asking about how to contact us and for future presentations.
- Others asked if they should start developing a local advisory group in their region. Brenda told them to go for it since we need as many small regional groups as possible to represent the diversity of the province, and to have more advocacy and more voices.
- Brenda carefully addressed that people with dementia are the number one stakeholder. She made a joke about if it wasn't for people with dementia, then most of them wouldn't have a job.
- Lisa expressed how amazing Brenda's presentation was. People were understanding and getting all her points, she got a standing ovation.
- Lisa has a list of people interested in the engagement document, knowing about the group, and engaging with the members of the group. We need to figure out how to manage these request.
- David Harvey received donations for ODAG at the event. He also donated his honorarium to ODAG, along with another speaker as well. ASO's financial department will manage these donations for us.
- This was the first big event that ODAG had been referred to and it was clear that people see the value of our work.
- There was a panel discussion and there were a lot of questions that came Brenda's way.
- Brenda was glad that there was a question about peer support because lots of chapters don't seem to understand its importance, and it gave her the opportunity to reinforce the significance of peer support.
- Brenda and Lisa had a conversation with Linda Lee about making peer support/peer mentoring part of the memory clinics as she leads the training for these clinics.

### **3. Provide any updates or information learned since the meeting with Indira; next steps with Indira moving forward**

- David and Delia had a meeting the senior policy advisor and staff. It was clear that Indira received our message and she was able to share it with her staff.
- Delia could tell that they had been briefed well with what Indira learned from the meeting and what she took away from it.
- Indira is very eager to start meeting with other groups and stakeholders. She would like to meet with as many people as possible.
- They are also reviewing their engagement plan.
- Delia reinforced that when they are considering the idea of an expert, they need to move away from its traditional meaning as people with dementia are the experts. This was well received and it will happen if some sort of panel were to be developed.
- The staff was very intrigued about the documents that we developed and how to apply them.
- Questions about our contact person and how to share the engagement document came up so we need to have a discussion around these topics.

### **4. Discussion around having a contact person for the group**

- Brenda expressed that usually in businesses, there is one contact person. However, she experienced having a group as a whole be the contact and it worked very well, and she sees this group using that method.
- Another important point is that in general, people with dementia should not have person contact information going out for safety reasons.
- People will contact us as a group and whoever is available will take care of it.
- It was suggested that we should have one central email address that can be linked to the email of each member of the team (individuals and supporting organizations). Delia will look into creating this.

### **5. Discussion around how we want to share the engagement document?**

- Should we send the document proactively or have people request for it and then we send it out?
- Before sharing the document, Mary Beth and Delia will update the document with the following minor changes:
  - The document is targeted for Indira so we need to generalize it
  - Create a cover letter for it
  - Add all the organizations on the bottom of the document
  - Add the date
- We have to be proactive in communicating that we have this document.
- People in regional dementia advisory groups should be the first to receive this document.
- This document should be put on the website as a pdf, ready to download.

- Note that this document is not set in stone. It could be updated as we move along and learn more information.
- The document has to be dated so when we do make changes in the future, a revision date can be added on.
- Once the document has been revised, all chapters of the Alzheimer Society in Ontario should receive it and ASO will be happy to send this out.
- ASO's e-newsletter could be another way to circulate the document.
- We need to compile the list of people who are currently asking for the document. Lisa will send the document to these people once it is revised.
- During our next meeting, we will work on creating a list of people to send the document out to.
- Delia will come up with a list of the regional advisory groups.

## **6. Discussion around group membership**

- It would be very difficult to have a teleconference with a lot of members. Lisa is wondering if we need to start trialing all the options available for web conferences.
- No matter how many members there are, we always need an odd number of people for voting purposes. Therefore, we do not need to implement anything for tie breakers.
- It was decided that there should be no more than 7 people in the group, but there is no rush to fill the last 2 spots. Somewhere along the line, we can look into filling those spots with people representative of the minority.
- We should spend more time getting people to create regional groups instead of expanding our group since we will receive feedback from those groups.
- Should we call ourselves a steering committee? However, we would not want to change the group name.

## **7. Website**

- We are looking to rely on our supporting members to update or do any housekeeping stuff for the website.
- It is not expensive to get a website. It is around \$10/year for a domain name.
- Some of the suggested domain names were odag.ca, ontariodementia.ca, dementiaadvisory.ca
- It was brought up that for a stranger, ODAG doesn't mean anything, while ontariodementia indicates that the site is about dementia and it is provincial.
- It was decided to secure both odag.ca and ontariodementia.ca. Both domain names will lead to the same website and when we get more publicity, we can look into just keeping one.
- Along with the domain name, a host site is also required. Elaine suggested that we should go with weebly.com. It is what she used for the rethinkingdementia.ca site, which you could check out as an example.

- The starter package is \$3.29/month and the pro package is \$6.63/month.
- Elaine recommended to get the pro package as it includes a private password feature. We would be able to upload files and make them accessible only to those who have the password.
- It is a very intuitive system and very easy to work with, and Elaine is more than happy to take care of the website.
- Lisa offered to be added as an administrator for the website as well just in case additional support is needed.
- Elaine will secure the domain names and develop a template of the website for the group to review at the next meeting.
- So far the website will include an introduction page, news, upcoming events, contact us page, and bios of the group.
- For the bios of the group, we can use the profiles that were created for Indira and modify them as needed.
- Elaine won't put up actual content or pictures on the template until they are finalized by everyone.

#### **8. Discussion around managing requests for engaging with ODAG members**

- Lisa has received 4 requests from people wanting to engage with the ODAG members. Some examples of these requests include:
  - A woman from St. Joseph's Health Centre in Guelph is interested in the engagement document, and she would like an opportunity to speak to the group.
  - The Geriatrics Health Systems Research Group in the University of Waterloo is looking to create a dementia strategy in the KW region so they would like to talk to the group.
- For dealing with these type of requests, should people fill out a requisition form that states what they would like to discuss and some suggested meeting dates?
- We definitely need an agenda from the people requesting to meet with us.
- If it is not possible to have everyone participate in the meeting, at least 2 members should be present. We also need 1 support person to help facilitate and take notes during these meetings.
- It would be great to have an internal calendar on the website so the group can be aware of all the meetings, events and etc. We will ask Elaine to see if the website has the capacity to do this.
- We also need feedback from all the people that request to meet us.
- Lisa will get more information and details about these requests and circulate it through email if it's urgent, or bring it up during the next meeting.

#### **Action Items:**

- Elaine will book a teleconference line for next meeting.
- Giselli will send out the meeting minutes and agenda.

- Delia will request to get some reflections from Indira about the meeting
- Delia will look into creating a central email address for the group.
- Mary Beth and Delia will revise the engagement document and create a cover letter.
- Lisa will send the engagement document to the people currently asking for it once it is revised.
- Delia will come up with a list of the regional advisory groups in Ontario.
- Elaine will secure the domain names and develop the website template to be reviewed at the next meeting.
- Lisa will get more information and details about the meeting requests.

**Next meeting:**

**Monday, March 2<sup>nd</sup>, 2015**

**10:00 am – 12:00 pm**