

Ontario Dementia Advisory Group

Meeting Minutes

Monday January 26th, 2015

11:00 a.m. – 12:30 p.m.

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

Regrets: Phil Caffery, Maisie Jackson

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 January 19th, 2015

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

2. Updates and information regarding the meeting with the Ontario government

- Delia heard back from Indira's executive assistant and our meeting has been booked for Wednesday, February 4th at 2:00 p.m. – 4:00 p.m.
- It seems like we will not receive any support for travel costs as Indira's executive assistant informed Delia that there is no budget line to cover travel for stakeholders. However, Delia asked her to check if there is funding for transportation within Indira's budget for developing the strategy.

- For now, we will assume that we will not be receiving any external funding for our transportation needs and we should keep this in mind during our discussion around the meeting location.
- The key thing to consider when determining the meeting location is what the easiest option is for our 2 members travelling from Thunder Bay.
- Elaine could support Bill's travel costs regardless if there is funding from the ministry.
- It is important for Bill to be physically present at the meeting, and Elaine would be able to connect to the meeting remotely if she is not able to make it in person.
- Delia would be able to pick up Bill at the Toronto Island Airport and drop him back off as well.
- With all these things taken into consideration, it was confirmed that Niagara will host the meeting. Delia will submit this location to Indira's executive assistant.
- Brenda will let us know on Wednesday if she will be able to attend. Mary Beth will connect to the meeting remotely as well.
- We need to do a trial run for whatever platform we decide to use to connect to the meeting remotely. Currently, skype seems to be the most viable option.
- There was a discussion regarding if the presence of a CEO or board member was necessary to greet Indira at the door.
- It was decided that the CEO or board members should not be doing any of the greeting or be involved in the meeting as the meeting is about getting our message across to Indira, and not about trying to display the authorities present.
- For this meeting and any other meetings in the future, we have to be clear on the objectives of the meeting and who needs to be there to support these objectives.
 - We need to explore the purpose of both the meeting, and each person that will be present in the meeting.
- It was determined that Delia will be the facilitator for this meeting since she has been positioned between this group and the government. She will be able to guide the discussion, and keep both groups on track.
- Giselli will be the note taker.
- It is really important for the people with dementia to have good support, and so during this meeting, the members of the group without dementia will take on this role.
- Those with dementia will be at the forefront of the discussions, but the other group members will be present to help them.
- Regarding the breakdown of the day, it was asked if we were going to be answering questions from the government or leading the conversation.
- Based on Delia's discussion with Indira's executive assistant, it seems like we would be able to lead the conversation, but they might ask questions regarding the next steps for the strategy.

- Our group is setting the agenda, and sending Indira and her staff reading materials so we are responsible for the direction of the discussion, but they may have their own questions as well.
- We do not have a backup meeting date, however if the meeting is cancelled due to weather related issues, we could easily reschedule.
- It was also brought up that we need to figure out the philosophy of this group, but we will tackle this on a later date.

3. Finalize the executive summary (ODAG – Engagement and Involvement in Public Policy document)

- The following are key revisions made to the document after our last meeting:
 - A forward was developed to explain the importance of the document
 - “Meaningful” from “Meaningful Engagement” was removed so there is more focus on just engagement
 - A tagline was added in the footer – “Nothing About Us Without Us”
- Regarding the citation of the documents we used for information:
 - The Authentic Partnership Approach was developed by MAREP
 - Elaine will get back to Delia on how to cite the Meaningful Engagement Framework
 - As part of the citations, the web links to each document should be added
- The summary should be highlighted in a more eye catching way. It could possibly be put into a text box.
- Throughout the document, “challenges” should be used instead of “deficits” as it shift the perception from negative to positive.
- “Care partners” will also be used rather than “caregiver”.
- In the 1st page, 4th paragraph, the sentence, “Being unable to express what we feel or what we wish to communicate can create frustration for the person” was removed. It suggested that people with dementia were unable to voice their opinions all the time, but it is only sometimes. This is also explained later in the document so it does not need to be included here.
- In the 2nd page, the sentence, “Be prepared to deal with any unacceptable practice that comes to light during the process” was changed to “Be open to adapting your practices based on feedback from people with dementia received during the process of engagement”.
- In the 4th page, the 1st bullet, “Be aware that there is the possibility that some people with dementia will be subject to poor practice or abuse, and be prepared to deal with this” was removed. There were issues with the words, “poor practice or abuse”. It was also concluded that this sentence did not enhance the document.

- Regarding the formatting of the document:
 - There are concerns that there might be too many different fonts
 - We need to make the “Nothing About Us Without Us” footer more prominent
 - The “Ontario Dementia Advisory Group” header should only be on the first page
 - Mary Beth will attempt to reformat the document
- Delia will send out the final PDF of the executive summary to the group, and then send it to Indira and her executive assistant no later than Thursday.

4. Reviewing the profiles of our group members

- A picture of Bea is needed. There is a picture of Bea and Brenda together, and possibly one with just herself. Gina will send it to Mary Beth.
- The following changes should be made to Bill’s profile:
 - Under background, change “Currently: Raises, trains, and shows Quarter horses” to “Bill and his wife, Heather own and operate Amethyst Farms; under which they have raised, trained and shown registered quarter horses”
 - Under highlights:
 - Add “Feb 1st, 2015 will be his ninth year acting as honorary chair for Thunder Bay Walk for Memories”
 - Champion is also spelt incorrectly
- The following changes should be made to Brenda’s profile:
 - Use the standard picture that she uses in other communications. Lisa will send this to Mary Beth
 - Under background:
 - “Was a registered Industrial Accountant” should be “Retired Industrial Accountant”
 - Add “Mother of 2, Grandmother of 4”
 - Under highlights:
 - Change the word, “current” to “present”
 - Modify the 3rd bullet to “2002-present volunteer of MAREP”
 - Change the word, “instrumental” as Brenda does not like this word
- The following change should be made to Maisie’s profile:
 - Under background, it should say “Retired Director of Sales & Marketing in hotel industry”
- The following changes should be made to Bea’s profile:
 - Under background:
 - Add “Retired Nurse”
 - Add “Mother of 4 children, Grandmother of 8”

- Under highlights, mention that she is an advocate
- Mary Beth will revise the profiles of our group members and Giselli will help with finalizing it.
- The group should email Mary Beth directly for any other changes, but keep in mind that Delia needs to send this out by Thursday.

Action Items:

- Giselli will send out the meeting minutes and agenda, and assist with finalizing the profiles of our group members.
- Elaine will send Delia the proper citation and web links to Delia for the documents.
- Lisa will send the web link for The Authentic Partnership Approach document, and the standard picture of Brenda to Delia.
- Mary Beth will reformat the executive summary and revise the profiles of our group members.
- Gina will send a picture of Bea for her profile to Mary Beth.
- Email Mary Beth before Thursday if you want to make any other changes to your profile.
- Delia will send out the final PDF of the executive summary to the group, and then send it to Indira and her executive assistant no later than Thursday. She will also submit Niagara as our meeting location.

Next meeting:

Monday, February 2nd, 2015

11:00 am – 12:30 pm