

**Meeting ODAG
February 2, 2015**

**Present: Nancy, Bea, Gina, Delia, Lisa, Brenda, Mary Beth, Bill, Elaine, Maisie
Regrets: Giselli**

Review of meeting notes from January 26, 2015

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

Updates from Delia

- Delia sent materials off to Samantha, Indira's executive assistant, and Delia will have a conversation with her this afternoon to prep Indira this afternoon.
- All looks good on their end.
- It's easier for Indira to travel to those groups rather than for stakeholders to come to her.
- Delia spoke with Tina, CEO of Alzheimer Society of Niagara, that AS-N's role is to facilitate the conversation, not to be a part of it. There will be an introduction of Tina at the meeting, and then she will leave.
- Mary Beth asked—what the government hopes to obtain? They want to know how to work with people living with dementia during this process. Methods of engagement might come up. They will note where the other working groups are. At the end, there might be discussion about possible ways to move forward. For example—the 10 points that were brought up by Mary Beth and her group previously.
- We will highlight that people living with dementia bring a different perspective and it needs to be heard, and what is different when engaging people living with dementia rather than assuming care partners to speak on behalf of people living with dementia.
- Nancy will look into ensuring that we have identified all advisory groups across the province of people living with dementia and that we have a list for Indira.

Logistics of the Meeting

- In Niagara, Erin did a test run with Skype with Nancy, Mary Beth, in the TLC room.
- Gina asked if we should have comfortable furniture or have tables set up. Bea stated that she works best with a table between us. A table and faces are the least amount of distractions. Having all the documents in front of us will be helpful. We will make sure that everyone is mixed in together, not with the group on one side of the table and the government on the other side.
- The group would like to have in front of them the key points that we want to cover in the meeting. An agenda with some key points will be developed. Pictures of who the people are will be helpful for the group too to have in front of them for that day.
- Lisa will print out tent cards for everyone so there are name tags there for people.

- Lunch will be in the kitchen at the Alzheimer Society of Niagara from 12:30-1:45. Gina asked if there are any food allergies she should be aware of.

Proposed agenda for the meeting:

- Introduction - 15 min.
 - Discuss ODAG Engagement document 40 minutes
 - Discuss PALWDD - 10 recommendations 40 minutes
 - Next steps 25 minutes
 - Conclusion 5 minutes
- Mary Beth asked what is the most important thing for us to cover so we are clear with our time. It was agreed that it was all important, with the focus on the Engagement document.
 - The introduction will be important to get people talking. People will introduce themselves. People don't want to spend too much time on themselves, but want to get into the meeting. "A Table Introduction"—just a couple of sentences is sufficient. If there are other items not on the written profile, you can add it in.
 - An overview of the group will help to frame the day. Delia will do thank yous and introductions, and a little bit about the group, then everyone will do a table introduction.
 - Delia will then ask Indira to give an overview of her mandate for the group.

Engagement Document

- Mary Beth suggested that we develop an "elevator pitch", maybe about 3 or 4 points. This group needs to be central to the development of the Ontario Dementia plan.
 - Nancy suggested the summary from the engagement document. "Doing with not for" is key. In the agenda, having the key points will be really important.
 - Three key points were discussed:
 - 1) Nothing about us without us: we need to be central.
 - 2) Doing WITH, not FOR
 - 3) We are the experts
- It is important for us to have key bullet points, and we need to have that in front of us that day so everyone can follow the conversation.
 - How are the points on the document reflected in the three points above?
 - We want to put an expectation on the government in how we want the government to work with us. We want to identify WHY and HOW, and to help the government identify this.
 - The WHY includes the top 3 points, and then Delia will bring in the HOW from the document. The top 3 points will include:
 - 1) We are the experts.
 - 2) Nothing about us without us.
 - 3) Doing WITH not FOR.

- On the agenda, we can reference with colours. The points on the agenda will also be highlighted in the same colour in the other document so we can cross reference.

Preparation for the Meeting:

- Mary Beth will call in about 15 minutes or 30 minutes before the meeting... perhaps at 1:20 p.m.? That will help to make sure we all know our tasks.
- There was a discussion about assigned speaking roles. If people have a certain point that they want to talk about, they can identify that and talk about it. We will bounce ideas off each other and trigger certain thoughts.
- Have sticky notes in front of each person, write them down, so people can remember what they would like to talk about.
- Delia will need to ensure that everyone has had a chance to talk, that everyone has a voice. In other meetings, we have a process person. Lisa will be the process person to identify that everyone has had a chance to talk, and give hints for people to stay on task if needed.
- It would be helpful to have one person take each of the three points or take all of the three points of the WHYs. It will be much more powerful for the group to talk about this than one of the facilitators.

PALWWD document:

- If there is time, we will discuss the 10 recommendations document from Mary Beth—"Canadian National and Ontario Dementia Plans: Input from those living with dementia".
- We need to decide on a couple of things there that we want to stress.
- One thing missing—not too much emphasis now that people are being diagnosed early, we need more programs and services for people living with dementia earlier. We need to have more information too.
- Identifying next steps rather than identifying solutions. These recommendations may be taken as solutions, so we need to be clear about that these recommendations are not solutions. We should be clear that there should be a balance between what people want, not what the government thinks they need. We need to be aware of the diversity of groups of people living with dementia at different points along the dementia journey.
- We will frame the document identifying that this is the beginning of the conversation. As experts, there has already been some preliminary work in this area. This is an example and there is more to come. Our next steps: we make connections with other small units with advisory/working group and everything funnels through us. We can collate this information together. Ideas from across the province can come to us. Let Indira know that this is the goal—that every single person with dementia has the opportunity to share his/her perspectives.
- Perhaps each advisory group across the province can identify top recommendations and/or priorities, and then the provincial group can identify and collate together.
- This brings us to the end of the agenda—conclusions, thank yous, etc. by Delia

- Delia will get the documents to Gina for printing. We will convene as a group giving enough time to have discussion about the agenda.
- In the future, we will look at what we can do with web-based platforms so that we can follow along with the conversation and see everything.

Meeting adjourned at 1:00 p.m.