Dementia-Friendly COMMUNITIES

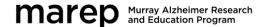


Dementia-Friendly Communities
Pilot Program Evaluation Report



Acknowledgements

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1. Executive Summary

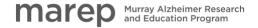
The Blue Umbrella (BU) Program is a new dementia-friendly communities (DFC) initiative being piloted by the Alzheimer Society of Ontario. The purpose of the program is to create a dementia-friendly business/service sector that is inclusive of people living with dementia and care partners.

The research team at the Murray Alzheimer Research and Education Program (MAREP) conducted an evaluation of the program in three pilot communities: Alzheimer Society Durham Region, Alzheimer Society Sault Ste. Marie & Algoma District, and Alzheimer Society Waterloo Wellington. The purpose of the evaluation was to examine the process of implementing the Blue Umbrella Program and the effectiveness of the training. Using a Participatory Action Research (PAR) approach and a mixed method design, the evaluation involved questionnaires, interviews, and observations. Additionally, "stories of change" were drawn from participants' lived experience and collected on an on-going basis, as an opportunity for critical reflection and discussion.

The evaluation found that the Blue Umbrella Program provided a opportunity for people living with dementia to be included in their community by participating in the development of the program and its delivery. Additionally, participants within the business/service sector valued the ability to learn about dementia first-hand from a co-facilitator with lived experience. Staff enhanced their communication skills, gained confidence interacting with people living with dementia, and learned to connect with individuals by supporting their reality. Staff reported that the education was applicable not only in the workplace, but also in their personal lives.

In terms of process, each local Society adopted a slightly different approach to program implementation—however, in all cases, establishing a local advisory committee was a critical first-step. This evaluation recommends that a consistent process be developed to support local Societies in launching the Blue Umbrella Program, and for on-boarding staff and co-facilitators with lived experience. Further, businesses should be provided with more time to apply the training strategies and make changes to their policies and practices before following-up with the local Society to receive the Blue Umbrella decal.

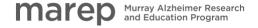
While businesses and organizations benefitted from the Blue Umbrella training, further research is required to determine the extent to which, and in what ways, the program empowers people living with dementia to remain active and engaged in their community. Further funding will be essential to sustain the benefits of the program. It is hoped that the findings from this evaluation will support the Alzheimer Society of Ontario in expanding the Blue Umbrella Program and other dementia-friendly community initiatives across the province.



2. Background

Dementia is an umbrella term used to describe conditions that affect memory, communication, and the ability to perform day-to-day activities. According to a report issued by the Alzheimer Society of Canada in 2010, more Canadians will become affected by dementia. In 2038, it is anticipated that over 1 million Canadians will be diagnosed with dementia—a 50% growth within the next 15 years. According to the World Health Organization, with a growing population affected by dementia, either living with or supporting someone who has dementia, the demands on local communities and the health care system are reaching critical levels.

New approaches to managing the impact of dementia are needed. While there is currently no cure, there is evidence that individuals who remain active and engaged in social interactions may be able to experience some delay in the progression of their symptoms. New dementia-friendly community initiatives, such as the Blue Umbrella Program, are being piloted in communities across Ontario, in order to create supportive and inclusive communities for people living with dementia. Such programs aim to enhance the wellbeing of people living with dementia and encourage them to participate in all aspects of community life.



2.1 What is a Dementia-Friendly Community?

A Dementia-Friendly Community is a place where people living with dementia are understood, respected and supported; an environment where people living with dementia feel confident that they can contribute to community life.

In a Dementia-Friendly Community, people will be aware of and understand dementia; people living with dementia will feel included and have choice and control over their day-to-day lives and level of engagement.

A Dementia-Friendly Community...

Understands	 Understands dementia and the challenges that people living with dementia face in their community
Includes	 Includes people living with dementia in all aspects of community life
Encourages	 Encourages and promotes the independence of people living with dementia
Assists	 Assists people living with dementia in the most appropriate and helpful ways
Values	 Values and welcomes people living with dementia in their businesses and establishments

Each person living with dementia will have different needs as they go about their daily activities in the community. By making a community more dementia-friendly, its businesses, organizations, and community members will be better able to assist people living with dementia in the most appropriate and helpful ways.



2.2 What is the Blue Umbrella Program?

The Blue Umbrella (BU) Program is a new dementia-friendly community initiative being piloted by the Alzheimer Society of Ontario in several communities across Ontario. The program is based on a successful pilot that was conducted in a rural community in Ontario. The purpose of the program is to create a dementia-friendly business/service sector that is inclusive of people living with dementia and care partners, within which people living with dementia are active and engaged, and provided with appropriate supports.

Objectives of the Blue Umbrella Program

 Empower people living with dementia to have confidence, keep active, and remain engaged in their community and in service/quality improvement

Empower People Living with Dementia



 Educate business/service sectors to be sensitive and responsive to people living with dementia and care partners, leading to positive interactions

Educate Businesses



 Challenge stigma and build greater awareness and knowledge of dementia by targeting business/ service sectors

Challenge Stigma



 Develop business partnerships to promote growth and ongoing development of the Blue Umbrella Program and sustain benefits

Develop Partnerships

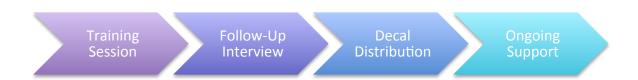


As part of the program, businesses and organizations have an opportunity to receive education about dementia, and learn strategies to provide good customer service to people living with dementia. The education activities are designed to build the business and service sector's knowledge and understanding of dementia, and to develop their skills in creating enabling and inclusive environments.

This education differs from traditional Alzheimer Society education in that it is delivered in partnership with people living with dementia and/or care partners.

The training is delivered by Alzheimer Society staff in partnership with a co-facilitator with lived experience. After the training session, Alzheimer Society staff follow-up with the head of the business or organization. Once a business has adopted the strategies from the training, it will receive a Blue Umbrella decal to display in its window, which designates it as a dementia—friendly establishment. As an optional component of the program, the business can elect to receive a visit from a person living with dementia acting as a "volunteer advisor", who will document their experience at the establishment and provide feedback to the business. The business will then receive ongoing support from the local Alzheimer Society, as needed.

Steps of the Blue Umbrella Program



By looking for the Blue Umbrella decal, people living with dementia will be able to easily identify establishments that have been trained to provide good and respectful customer service to them and their families. Additionally, people living with dementia may choose to wear a self-identifier in the form of a blue umbrella pin.



Figure 1 - Blue Umbrella Decal and Pin

The Blue Umbrella Program enables businesses and organizations to provide a unique, high quality service to new and existing customers. More importantly, it helps to shape a community that is dedicated to the safety and engagement of all of its members.

3. Program Evaluation

3.1 Research Purpose

Using a Participatory Action Research (PAR) approach, the purpose of this research project was to monitor and evaluate the Blue Umbrella Program being piloted by the Alzheimer Society of Ontario in five communities: 1) Alzheimer Society Brant, Haldimand Norfolk, Hamilton Halton, 2) Alzheimer Society Durham Region, 3) Alzheimer Society Sault Ste. Marie & Algoma District, 4) Alzheimer Society Thunder Bay, and 5) Alzheimer Society Waterloo Wellington.

Each of the pilot communities began the Blue Umbrella Program at different times. For this reason, a greater amount of data was available for Societies that were further along in the process. Due to the timing of this evaluation and the availability of data from the pilot communities, we will be reporting on the results from three locations:

- Alzheimer Society Durham Region
- Alzheimer Society Sault Ste. Marie & Algoma District
- Alzheimer Society Waterloo Wellington

Further, this report will focus on the process of implementing the Blue Umbrella Program, as well as the effectiveness of the training sessions for businesses.

3.2 Research Questions

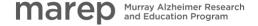
The objective of the research was to answer the following questions:

How have the knowledge, attitudes, skills and/or practices of the involved businesses and social services changed as a result of engagement with the project?

How has the Alzheimer Society's capacity to partner with people living with dementia, carers, and the business/service community been strengthened?

In what ways has the project built partnerships with the business/service community, and with people living with dementia and care partners?

How appropriate have the BU/DFC activities and tools been? Are there other strategies that would deliver better results for the investment?



4. Research Methodology

Using a Participatory Action Research (PAR) approach and a mixed method design, the evaluation involved questionnaires, interviews, facilitator reflections, and researcher observations. Additionally, "stories of change" were drawn from participants' lived experience and collected on an on-going basis, as an opportunity for critical reflection and discussion.

What is Participatory Action Research?

"Participatory Action Research (PAR) is an approach to research in communities that emphasizes participation and action. It seeks to understand the world by trying to change it, collaboratively and following reflection. PAR emphasizes collective inquiry and experimentation grounded in experience and social history. Within a PAR process, communities of inquiry and action evolve and address questions and issues that are significant for those who participate as co-researchers." [Reason and Bradbury, 2008]

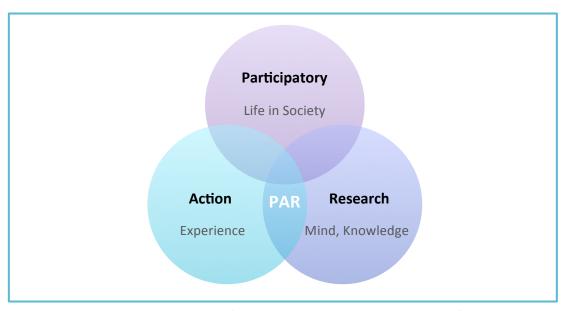


Figure 2 - Participatory Action Research [Adapted from Chevalier & Buckles, 2013]

As part of the PAR approach, an advisory group was formed at the local level in each of the pilot sites. The advisory groups consisted of people living with dementia, care partners, Alzheimer Society staff, and researchers. Staff from the Alzheimer Society of Ontario met with each of these groups and gathered their feedback to help determine the short, medium, and long-term goals of the program, as well as what aspects of the program should be evaluated. The input of the local advisory groups played a critical role in shaping a provincial evaluation framework for the Blue Umbrella Program.



4.1 Research Tools

Monitoring and evaluation activities were carried out at several points during the pilot program. These activities were conducted to provide stakeholders (e.g. ASO staff, local AS staff, advisory groups, and researchers) with early indications of progress, and to assess the progress being made towards achieving the desired program outcomes. In each of the pilot communities, the following Blue Umbrella evaluation tools were used to collect data. In most cases, local Alzheimer Society staff collected the data, which was then compiled and shared with the MAREP research team for analysis.

Partner Needs Assessment

- Completed by AS staff with businesses and organizations prior to receiving the Blue Umbrella training.
- Purpose: to develop rapport with the business and tailor the training session to meet their needs.
- Identified themes, issues, and recommendations for training, as well as any insights or ideas of the interviewer.

Training Evaluation Questionnaire

- Completed by training participants immediately after each session.
- Purpose: to receive feedback about the training itself, in order to identify areas that worked well and areas that could be improved.
- Included ranking scales, check-boxes, and open-ended questions.
- Took approximately 5-10 minutes to complete.

Volunteer Advisor Evaluation

- Completed by a "volunteer advisor" approximately 1-3 months after the the training. Where possible, the advisor was a person living with dementia and/or care partner wearing a Blue Umbrella pin.
- Purpose: to monitor the strategies being used to support people living with dementia and to provide the business with feedback and support.
- The advisor used a checklist to document their experience navigating the business environment and interacting with staff.

Alzheimer Society Staff Reflections

- Provided by Alzheimer Society staff during monthly webinars.
- Purpose: to reflect on experiences participating in the Blue Umbrella Program and co-facilitating the training.
- The MAREP research team asked open-ended questions and staff shared their verbal feedback during a webinar session, and in writing through e-mail correspondence.



Stories of Change

- Collected on an on-going basis over the course of the pilot.
- AS staff followed-up with the head of each business approximately 2-3 weeks after the training and asked them a series of reflective questions to collect stories of change.
- On an on-going basis, all staff were invited to share their stories via email.
- Purpose: to provide an opportunity for critical reflection and discussion by drawing on participants' lived experience and capturing elements of significance.

Researcher Observations

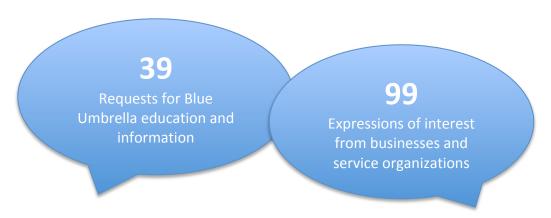
- A research assistant from MAREP conducted unobtrusive observations by attending the Blue Umbrella training sessions in the Waterloo-Wellington community.
- The purpose was to observe and document how participants responded to the training, including the types of questions being asked and suggestions for improvement that were provided during the sessions.



5. Program Statistics

At the end of each month, the local Alzheimer Societies recorded statistics on the Blue Umbrella Program. The following summary is based on all data recorded by the three pilot locations between August 2016 and May 2017.

Interest in the Program



Education and Training



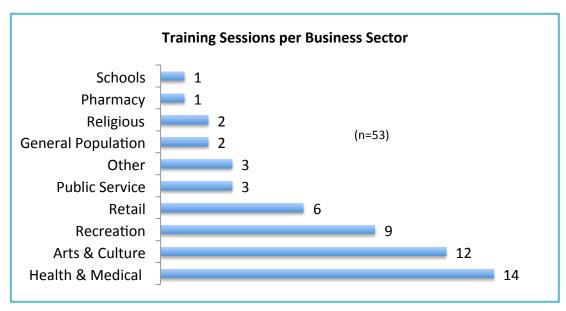


Table 1 - Training Sessions per Business Sector

In total, 53 businesses or organizations were trained in the three pilot communities. Most training sessions were delivered within the following sectors: Health & Medical (14), Arts & Culture (12), and Recreation (9). Over the course of the pilot, no businesses or organizations had yet to receive training in the following sectors: Transportation, Finance, Restaurants, Hospitality, and Community Agency.

Volunteering

Volunteers contributed 119 hours to the Blue Umbrella Program. In total, 27 volunteers were recruited, including 10 people living with dementia and 17 care partners. Of the 27 volunteers, 23 were trained to co-facilitate the training. Three additional care partners were not formally trained volunteers but offered their time to accompany people living with dementia in their



6. Results

For the purpose of this report, this section is organized into two parts: 1) Process, and 2) Training.

6.1 Process

Several things stood out with regards to the process of implementing the Blue Umbrella Program within the three pilot sites, including: the inclusion of people living with dementia, the ability to build partnerships, and the effectiveness of the training and tools.

Inclusion of People Living with Dementia

One of the key objectives of the Blue Umbrella program is to *empower people living with dementia*; empower them to have confidence, to keep active, and to remain engaged in their communities and in service/quality improvement. This dementia-friendly community initiative provided many opportunities for people living with dementia to become involved and empowered. These opportunities included participating on the Blue Umbrella Advisory Committee, co-facilitating the Blue Umbrella training sessions, and conducting "volunteer advisor" evaluations.

Participating on the Advisory Committee

In each of the pilot communities, local Alzheimer Society staff recruited people living with dementia and care partners to participate in the program. The group then worked to identify community partners, who in some cases included representatives from the local municipality, researchers, and other representatives or community members that were considered relevant to the program. Collectively, these individuals formed an advisory committee in each community to help implement the Blue Umbrella Program. Members of the advisory groups were engaged throughout the process and assumed many roles—they were instrumental in developing and promoting the program. In some communities, promotion included holding official launch events, hosting information booths, and mailing information letters to businesses. The advisory groups were heavily involved in these efforts, and the program would not have been possible without their involvement.

Staff mentioned that the majority of people living with dementia became engaged in the Blue Umbrella Program through existing dementia advisory groups. Some advisory group members came forward and volunteered for the Blue Umbrella Program, then recruited additional volunteers from other support groups or programs that they attended.



Roles of the Advisory Committee

Developing, testing, and revising program tools, including training content

Designing promotional items, including brochures and banners

Identifying potential sponsors in the community

Recruiting businesses and organizations to participate in the training

Recruiting volunteers to co-facilitate the training

Promoting the program and generating interest in the community

For one of the local Societies, engaging people living with dementia in the program was an ongoing challenge. Some staff found that the stigma around dementia discouraged residents from receiving an early diagnosis and connecting with the Alzheimer Society.

"We've observed strong apprehension from town residents to seek information and resources. This speaks to the pervasiveness of stigma and fear. As a result, persons with dementia in the community are getting diagnosed very late in the progress of their disease. As such, those individuals tend to not be an appropriate fit for the physical demands of the "walkabout" or education session. My hope is that with more public information, individuals will be diagnosed earlier and connecting with the [Alzheimer Society] sooner."

— Local Society Staff



Co-Facilitating the Blue Umbrella Training

Once a business or organization was prepared to participate in the training, local Alzheimer Society staff worked with the Blue Umbrella Advisory Committee to identify a person living with dementia and/or care partner to co-facilitate the presentation. Co-facilitating the training meant that individuals living with dementia could share their personal stories and experiences with the training participants.

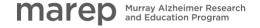
As a general training format, the co-facilitator shared their experience with dementia at the beginning of the session then assisted in delivering the training. At the end of the session, the person living with dementia and/or care partner answered questions about their personal experience, as well as general information about dementia and the Blue Umbrella Program.

Many of the training participants appreciated the opportunity to learn about dementia first-hand from a co-facilitator with lived experience. In particular, one respondent felt that the person living with dementia "made the training". Further, another respondent mentioned that the co-facilitator who spoke about their experience "put a face" to dementia. Some respondents found that the co-facilitator's charisma and use of personal anecdotes made the training more interesting.

"One of the best by-products has been the ability to include people living with dementia in a really meaningful way in the work that we do—giving them a very positive volunteer experience, and bringing them on basically as partners. We invite the person living with dementia to do part of the presentation, to talk about their experiences, to tell their stories... We take feedback from them, including what might help to enhance the presentation in some way."

— Local Society Staff

While people living with dementia were involved in co-facilitating the training, different approaches were used in delivering the presentation. For example, in some cases, the co-facilitator spoke about their experience at the beginning of the session, and Alzheimer Society staff delivered the presentation slides. In other cases, the co-facilitator spoke about their experience throughout the session, and delivered the presentation in partnership with staff. While both approaches were effective, the training was most impactful when the person living with dementia was more heavily involved in the presentation. This was evident in the feedback from the evaluation forms, and in observations on the quality of discussion during sessions. In general, participants asked more questions and were more engaged when the person living with dementia was involved throughout the presentation.



Conducting Volunteer Advisor Evaluations

As an optional component of the program, the business or organization could elect to receive a visit from a "volunteer advisor" approximately 1-3 months after the training. To conduct the evaluation, a person living with dementia and/or care partner visited the establishment to observe the strategies being used to support people living with dementia. The volunteer advisor completed the Volunteer Advisor Evaluation Form (see Appendix D) to document their experience navigating the environment and interacting with staff. The purpose of their visit was to provide feedback to the business and to determine if additional training sessions might be helpful. In cases where the advisors identified opportunities to improve the experience for people living with dementia, their feedback was provided to the business during follow-up discussions.

Some local Society staff mentioned that the program provided an opportunity to include people living with dementia as partners in their work. Staff also mentioned that they had seen more people becoming meaningfully engaged with the Society in other ways. For example, one of the Blue Umbrella co-facilitators approached a local Society and suggested new ways for people living with dementia to be included in program delivery (e.g. teaching children in schools).

Although people living with dementia informally spoke about their involvement in the Blue Umbrella Program as being very meaningful, the experience of people living with dementia in the program was not formally evaluated.

Developing Partnerships for Success

Before businesses and organizations received the training, local Alzheimer Society staff met with potential partners to conduct a Partner Needs Assessment (see Appendix A). The assessment provided an opportunity to develop rapport with the business and identify any themes, issues, and recommendations for the training. Approximately two weeks after the training, a follow-up interview was held with the head of each organization. The follow-up discussion provided an opportunity to review the business implementation strategy, and to reflect on any changes to policies or practices that might have been made since the training. These encounters enabled the local Society to build stronger partnerships with businesses and organizations in their own communities.

One Society worked with the entire recreation department of their local municipality, as well as the Mayor and members of Council. They also began working with an elder mediation company, which provided a new opportunity to look at legal services.

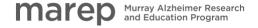


Another Society expressed that having champions in key organizations helped to quickly build rapport with residents and bring the Blue Umbrella Program to the businesses community. Further, its partnerships were strengthened through the advisory committee, which brought together the perspectives of a care partner, representatives from prominent businesses and health sectors, and a representative from the neighbouring First Nations reserve. Alzheimer Society staff mentioned that the diversity of the committee helped them to better understand the specific needs of community members, in terms of education and support.

"...The committee has been pivotal in helping to create concrete strategies for promoting the program in the community, approaching specific businesses, recruiting persons with dementia, and promoting our caregiver support group. They have the deep community knowledge to put me in touch with those key influencers and advocates of the DFC initiative." — Local Society Staff

One local Society mentioned that they received a grant and will be expanding the Blue Umbrella Program to a neighbouring community. For other Societies, staff mentioned that the Blue Umbrella Program enabled them to extend their reach into smaller towns and rural communities that otherwise might not have been aware of—or had access to—their services. As a result, the program helped to raise awareness of dementia-friendly initiatives among local residents.

"... For many in these communities, this is all new information. It has confirmed for me how vital initiatives like Blue Umbrella are for providing tangible support for residents in rural communities." – Local Society Staff



Effectiveness of Training and Tools

According to training participants and staff of the local Societies, the Blue Umbrella training session and tools were found to be quite effective overall.

The majority of participants mentioned that they felt the training was valuable and worthwhile. A few respondents even mentioned that many of the tips and strategies described in the training could be applied to interactions with many different groups in the community, in addition to individuals living with dementia.

"I learned about cues and directives specific to dementia, but most importantly the take away was to support different peoples' realities, however different they may be from my own. This applies to so many facets of mental health; approach with respect and understanding."

— BU Training Participant

"...The strategies provided in the training session apply to a host of situations with many types of people with cognitive disabilities."

– BU Training Participant

In particular, one organization valued their experience participating in the Blue Umbrella Program and organized an event to celebrate more than 100 staff members being trained. The respondents appreciated that the local Alzheimer Society was flexible and willing to schedule multiples training sessions to accommodate such a large team. The co-facilitators were invited to join staff as they debriefed on what they learned. Many staff members wrote down a key message that they took away from the training and posted it on a display board (see Figure 3).



Figure 3 - Comments Posted on Display Board at Celebration Event

Many participants liked the fact that the presentation was clear and concise. Others liked the fact that the presentation was informal. One of the participants found that the presentation was "very rewarding and could have used this awareness 20-25 years ago."

"[The presentation] was clear, straightforward, and factual with good balance of anecdotal information."

— BU Training Participant

Participants also expressed that the information was presented at a comfortable pace and that the presentation was "up-beat" for what could be considered a "depressing subject." Participants also found that the videos and stories shared by the facilitators were extremely helpful in understanding different perspectives. Most participants mentioned that they enjoyed the discussion period and felt that a safe space was created for asking questions.

In some cases, it was necessary for staff to adapt the presentation to better fit the needs of the organization, as the content of the training did not fit the context of the organization. This was particularly true for churches and not-for-profit groups.

As an area for improvement, participants felt that an additional handout should be provided, perhaps of the PowerPoint slides and a list of the resources mentioned throughout the presentation. This would enable participants to follow along with the presentation and to refer back to the resources when necessary. Additionally, some participants felt that the training could have been longer to allow for more opportunities for discussion and questions. Participants suggested making the presentation more interactive by providing greater opportunities for group discussions, case studies, and role-play scenarios.

"...It could be beneficial to include more participatory elements." — BU Training Participant

One respondent mentioned that staff of their organization found the summary sheets of Communication Tips (see Appendix G) very useful, particularly for those working at reception since they are the first point of contact with customers. The organization is now using the sheets at their front desk as a subtle reminder of how to communicate and provide appropriate customer service to all individuals. In addition, another respondent mentioned that their organization plans to share the materials provided at the training session with any new staff, as a means of ensuring that all employees are informed and knowledgeable of the program.



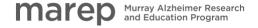
For local Societies that experienced challenges involving people living with dementia as cofacilitators, staff relied heavily on videos to provide a first-person perspective from an individual with lived experience. Specifically, staff mentioned that the videos from Rethink Dementia and Alzheimer's Australia made a significant difference in the education sessions. However, in some cases, presentations were impacted by challenges with technology (e.g. low volume or no sound on video clips). In light of the challenges, participants commented that the facilitators handled the situation well.

In some cases, local Society staff adapted the Blue Umbrella tools by creating online versions of the surveys rather than distributing paper copies, which helped to offset the administrative load. Similarly, some staff commented that it would be ideal to create an online version of the entire training, as a means of sustaining the Blue Umbrella Program. An online format would also enable new staff of the participating businesses and organizations to remain current on the training.

Finally, in some communities, the Blue Umbrella pin was not widely adopted. In one community, staff mentioned that the people most interested in wearing the pin were those wishing to show their support for "someone else". Staff suggested that perhaps another wearable item could be developed for care partners and supporters of the program.

Overall, the Blue Umbrella training was very well received and respondents felt that sessions should continue to be offered to more businesses and organizations.

I find it encouraging to know that the Blue Umbrella project exists and that businesses and institutions like ours are receiving the tools we need to make people living with dementia feel welcome... I wish that everyone could receive this training; you never know who might be affected by dementia... Knowing that we are part of a Dementia-Friendly Community, makes me feel proud knowing that those living with dementia have one more place that they can visit and call their own with a sense of ease and confidence." — BU Training Participant



6.2 Training

Partner Needs Assessment

Once a business or organization had expressed interest in the Blue Umbrella Program, local Alzheimer Society staff conducted a Partner Needs Assessment (see Appendix A) to learn about the business and tailor the training to meet its needs. The following is a summary of findings derived from 27 partner assessments conducted between November 2016 and May 2017.

What experiences did partners have with people living with dementia?

Partners were asked to describe any experiences their business had with people living with dementia. Of the 19 businesses that responded, the majority (55%) mentioned that they have some customers who are living with dementia. Further, half of these businesses mentioned that memory loss is often a challenge for their customers and a few respondents described specific scenarios, including: forgetting PIN numbers, forgetting to return library books, losing their way in the store, purchasing multiples of the same items, and repeatedly calling and asking the same questions. In addition, other businesses (17%) suspected that some of their customers might be experiencing symptoms of dementia. A few businesses (17%) did not have any experiences with customers living with dementia; however, they felt the training would be beneficial for any staff with personal connections or family members living with dementia.

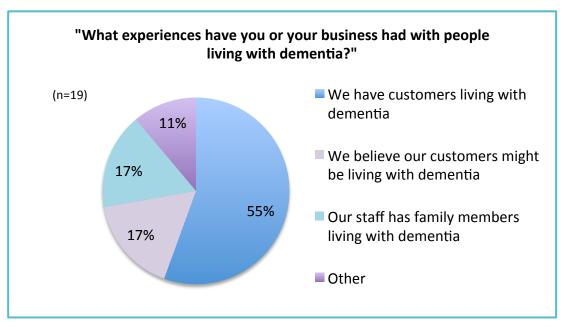


Table 2 - Partners' Prior Experiences with People Living with Dementia



What did partners hope to learn from the training?

Partners were asked to describe what they would like to learn from the training session. Of the 25 businesses that responded to this question, the majority (52%) were interested in learning general information about dementia. Other partners (30%) were interested in learning communication strategies in particular. Certain businesses (6%) had already completed staff training in other areas (e.g. accessibility training) and were interested in building upon their knowledge, in order to establish a reputation as having a welcoming environment for people living with dementia. Other businesses (6%) were interested in learning how to identify and respond appropriately to personal expressions. Of the businesses interested in learning about prevention tips (3%), the respondents were interested in receiving information on early stages of dementia and where to go for assistance.

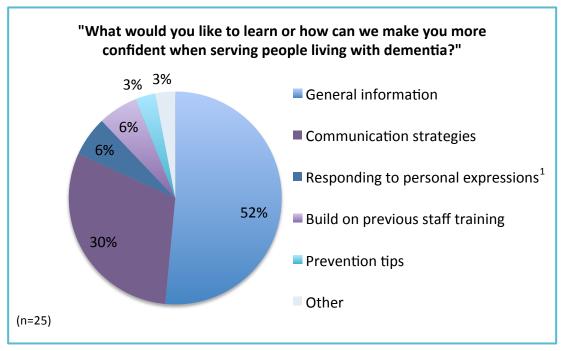


Table 3 - Partners' Needs and Learning Interests

¹ Personal expressions refer to actions, words or gestures that are a response, often intentional, to something important to people living with dementia, including their personal, social, or physical environment.

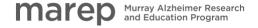
Training Evaluation

Who participated in the training sessions?

Immediately after each training session, Alzheimer Society staff administered the Training Evaluation Questionnaire (See Appendix B & Appendix C) to get feedback on the training itself. Two versions of this survey were used in the evaluation, as changes were made to the evaluation documents mid-way through the pilot period. For this reason, some questions received more responses than others, as not all questions were included on both versions. In all cases described below, the total number of responses is denoted by the term "(n=)".

Over the course of the pilot, 438 training participants completed a Training Evaluation Questionnaire in one of the three pilot communities, resulting in a 57% response rate.

Location	Surveys Completed
Durham Region	15
Sault Ste. Marie	125
Waterloo Wellington	298
Total	438



Who participated in the training sessions? (Continued)

Participants were asked to select a category that best described them. Of the 319 participants who responded, the majority (59%) were staff members of the businesses and organizations that were participating in the program. Further, volunteers of those organizations also participated in the training and accounted for more than half (66%) of the responses in the "other" category. Additionally, some community members (15%) attended the training out of general interest as an opportunity to learn about dementia. A smaller portion of participants (11%) were supporting a person living with dementia, and only one person identified as an individual living with dementia.

Some participants identified with more than one category (e.g. a staff member who was also supporting a family member living with dementia). In these cases, their responses were counted under both categories.



Table 4 - Participants in the Blue Umbrella Training

¹ This category also included people living with memory loss and mild cognitive impairment.

How much did participants know about dementia?

Participants were asked to rate their prior knowledge of dementia-friendly supports. Of the 199 participants who responded, approximately 46% indicated that they had "good" knowledge prior to receiving the training, followed by 34% who indicated that they had "fair" knowledge. Approximately 13.5% of participants felt that they had "very good" knowledge, while 6.5% reported that they had "no prior knowledge".

To some extent, prior knowledge varied according to the type of business or organization being trained. For example, in some cases, staff of arts-based establishments had less prior knowledge of dementia than staff of health/medical organizations.

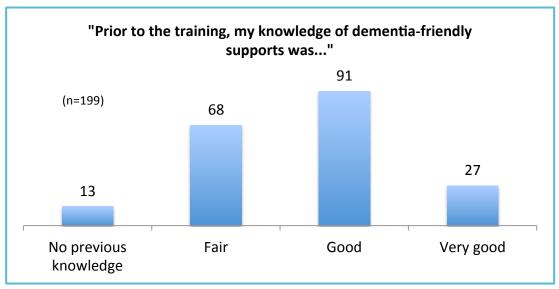


Table 5 - Participants' Prior Knowledge of Dementia-Friendly Supports



How did participants rate the training format?

Participants were asked to rate several aspects of the training format using a five-point scale, from 1 (strongly disagree) to 5 (strongly agree). All aspects of the training were rated highly and received average scores greater than 4 out of 5.

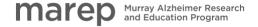
The highest rated aspect (4.75 out of 5) was the pace of the session. Some participants who provided additional comments mentioned that they appreciated that the training was clear and concise, and presented at an appropriate pace that was not overwhelming.

The lowest rated aspect (4.31 out of 5) was the volume of material provided. While this aspect was still rated very high, some participants mentioned that they would have benefitted from additional information on dementia, such as current research, warning signs, and tips for prevention.



Table 6 - Participants' Ratings of the Training Format

Note: In some cases, it was likely that the respondents interpreted the rating scale backwards. For instance, they rated the aspects very low but made positive comments throughout the survey. These cases (n=6) were considered outliers and were omitted from the totals.



¹ For the first few training sessions, no handout was provided to accompany the presentation slides. For this reason, the criteria "the handout was a valuable resource" received fewer responses than the other aspects, as many participants simply left this question blank.

How did participants rate the training content?

Participants were asked to rate several aspects of the training content using a five-point scale, from 1 (strongly disagree) to 5 (strongly agree). All aspects of the training were rated highly and received average scores greater than 4 out of 5.

The highest rated aspect (4.67 out of 5) was the ability of participants to apply elements of the training not only in the workplace, but also in their personal lives. Some participants provided additional comments and mentioned that they intend to apply the training to help support their family members as well as members of the community.

The lowest rated aspect (4.45 out of 5) was the extent to which the content was relevant to the needs of participants in establishing dementia-friendly supports. While this aspect still scored very high, some participants mentioned that they would have liked the training to be more tailored to the context of their organization.

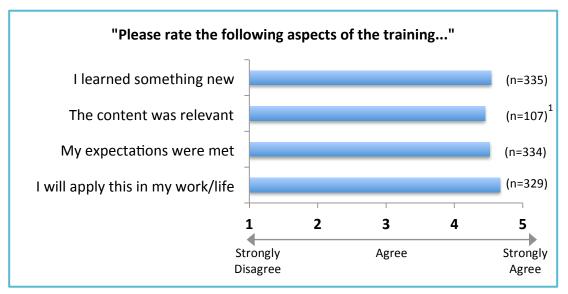
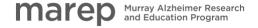


Table 7 - Participants' Ratings of the Training Content

Note: In some cases, it was likely that the respondents interpreted the rating scale backwards. For instance, they rated the aspects very low but made positive comments throughout the survey. These cases (n=6) were considered outliers and were omitted from the totals.



¹ This criteria was included only in the revised version of the Training Evaluation Questionnaire. For this reason, it received fewer responses.

How did participants rate the training overall?

At the end of the survey, participants were asked to rate the training overall, using a five-point scale from 1 (very poor) to 5 (excellent). In total, 222 participants responded to this question. Overall, the total average rating was 4.57 out of 5.



Evaluating the Blue Umbrella Program

The following themes emerged from the qualitative data collected in this evaluation, including the comment sections on the questionnaires, the follow-up discussions with staff and management of the businesses and organizations, the interviews with Alzheimer Society staff, and the collected Stories of Change. Common themes included: enhancing knowledge and awareness, shifting attitudes and perspectives, and putting knowledge into action.

Enhancing Knowledge and Awareness

Participants were able to enhance their knowledge and awareness of dementia in several areas, including: developing a better understanding of dementia, communicating with confidence, and learning appropriate strategies to support people living with dementia.

Understanding of Dementia

All respondents mentioned that their knowledge and understanding of dementia had increased as a result of participating in the training, particularly as some respondents had no previous knowledge of dementia. Specifically, some respondents mentioned that their *awareness* of dementia had improved and that they were better able to identify signs that an individual might be experiencing symptoms of dementia. Further, respondents learned that every individual is unique and will experience symptoms of dementia in different ways.

"Before completing the Blue Umbrella training,
I knew very little about Alzheimer's and other
forms of dementia. The Blue Umbrella training
filled the substantial gaps in my knowledge and
by understanding how the conditions manifest
and affect perception, I feel more
compassionate to those affected..."

— BU Training Participant

"I was amazed with how much
I was able to learn from our
training session and I believe
that it has benefitted my
performance in the workplace
and also helped with my
awareness overall..."
— BU Training Participant



While many participants enjoyed the presentation, some found that the content could have been better tailored to the audience. For instance, one participant indicated that the "content was aimed at a different level than was likely appropriate for clinical staff." Others found that they would have benefitted from more complex material.

"At times it seemed like general, common sense, customer service training. More detail on dealing with escalated situations." — BU Training Participant

Communication Strategies

Communication strategies were a common theme that emerged from the data. Since receiving the training, respondents mentioned that they became more patient and mindful of their tone and body language when interacting with people living with dementia. Additionally, respondents mentioned that they had changed their communication techniques, for example, making statements that are clear and concise, and using familiar language that is easy to comprehend. Others mentioned that they avoid asking multiple questions at once, and they check with the individual to confirm if they fully understood the message. Further, one respondent mentioned that they now make a point to engage with the person living with dementia, rather than their care partner. Overall, the majority of respondents felt that the training provided them with valuable tools to enhance their communication and as a result, they have become more confident when interacting with people living with dementia.

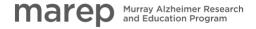
"From a professional perspective, I am more confident in my ability to identify signs of perceptual difficulties, and I feel better able to switch tactics when interacting with individuals living with dementia."

— BU Training Participant

"I have dealt with customers with dementia in the past and did not feel confident because I didn't know how to interact with them in an appropriate manner. I was afraid of doing or saying something wrong.

Now I feel confident that my interactions with patrons with dementia would be positive and that I would know what to do."

— BU Training Participant



Support Strategies

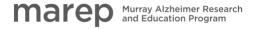
Participants found that the tips and strategies provided in the training could be applied not only in the workplace but also in their personal lives. Participants mentioned that they felt better able to communicate and engage with people living with dementia, and that the training provided them with practical tips on how to handle various situations. In general, participants felt that they left the training with a better understanding of how to support people living with dementia. Specifically, some participants commented on their new ability to accept the reality of the person living with dementia, particularly by "connecting – not correcting". Others mentioned that they became more compassionate and plan to build relationships with people living with dementia by treating them with greater dignity and respect.

Shifting Attitudes and Perspectives

As a result of the training, approximately half of the respondents mentioned that they felt a change in attitude towards people living with dementia. In particular, one respondent stated that they no longer "feel pity" towards people living with dementia because they have learned that individuals continue to possess many skills and abilities. Similarly, another respondent learned how "livable" having a diagnosis could be, and that people can continue to live well with dementia.

"After our Blue Umbrella/Dementia Friendly
Communities seminar at my place of employment, I
shifted my attitude about interacting with someone for
the first time. It made me realize that you cannot
assume anything about people and where they are
coming from. I will definitely keep more of an open
mind when initially meeting someone, remembering
that they may have invisible challenges that are
influencing our interaction..." – BU Training Participant

Other respondents mentioned that while they did not experience a change in attitude, they did develop a different perspective towards people living with dementia. By learning of the prevalence and impacts of dementia, they became more compassionate and empathetic in their interactions with individuals living with dementia. Others remembered the key messages and strategies from the training and were able to apply them in their personal lives, which gave them a new perspective when engaging with family members.



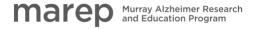
"As someone who has many loved ones affected by Alzheimer's and dementia, I found the training gave me a new perspective. The simple instruction to embrace their reality has changed the way I look at interactions with my family."

— BU Training Participant

For many participants, the presence of a co-facilitator with lived experience provided a powerful example of a high functioning individual living with dementia. The inclusion of a person living with dementia challenged the stigma surrounding dementia, as participants learned that people living with dementia have many skills and abilities.

"I never would have guessed. People that have dementia can be much more capable than I previously thought." — BU Training Participant

However, while participants generally left the training with greater knowledge and a new perspective of dementia, researchers noted that dementia-friendly language was not being used consistently in the evaluation forms. The terms "suffering" and "patients" were among those provided in the comments.



Putting Knowledge into Action

After receiving the Blue Umbrella training, participants were able to apply their new knowledge of dementia-friendly supports in their workplace. At each business or organization, a "volunteer advisor" visited the organization to monitor the strategies being used to support people living with dementia.

In total, Volunteer Advisors completed six evaluations over the course of the pilot program. In all cases, the advisors were people living with dementia accompanied by their care partners. The majority of advisors living with dementia chose to wear the Blue Umbrella pin.

Overall, the feedback from the evaluations was quite positive. At each establishment, the advisors reported that the person living with dementia experienced a good comfort level in the environment and with staff. In general, the actions of staff members were consistent with the strategies that were described in the training. For instance, staff were patient and approached people living with dementia with an open, friendly, and relaxed manner. Staff made eye contact and looked at the person living with dementia when speaking. They spoke slowly and asked simple questions, one at a time, and did not interrupt the person living with dementia. Where applicable, staff offered to take the person living with dementia to the item they were looking for. Volunteer Advisors provided the following comments on their evaluation forms.

"Overall experience very positive. Warm, welcoming, relaxed atmosphere... It was clear the usher saw the blue umbrella pin, but nobody commented upon it. When we entered [the establishment] the usher greeted us (me first [person living with dementia]), and then offered to take us to our seats. As we were getting seated she mentioned that if we needed anything else any of the volunteers were there to help."

— Volunteer Advisor

"There were some stairs...
They discreetly kept an eye
on us and made sure we
knew how to get out."

- Volunteer Advisor

"Staff exceptionally friendly to everyone. They did not know that [the individual] has dementia. Gave [us] another idea of a place to take the grandchildren."

— Volunteer Advisor



Out of the six evaluations, five concluded that no further training was required. However, in one case, the advisor suggested that further training should be held since staff did not appear to be aware of customers or attentive to their needs. The following comment was provided.

"Reception was friendly but had to be asked about exhibits, where washrooms were, etc. Did not ask us any questions. Staff did not make eye contact, say hello, or anything... We had our pins on and they were visible."

— Volunteer Advisor

Changing Policies, Practices, and Physical Environments

One respondent mentioned that the organization had made changes to its practices by simplifying the ticket-buying process for a customer living with dementia.

"We do have a patron who will often purchase more than one ticket to a concert, but they have now been flagged so our representatives will look to see if they already have a ticket before selling them a new one. It's not a difficult thing for us, and it will help to prevent further confusion. This is the direction I'd like to see us head toward, one where we are able to make ticket-purchases easy for everyone, including those living with dementia."

— BU Training Participant

While some staff did share stories of change, many respondents felt that the 2-week follow-up period did not provide sufficient time to make changes based on the training. For this reason, most businesses and organizations had yet to make changes to their policies and practices, and suggested that follow-up discussions should be scheduled at a later date. This was particularly true for one arts-based organization that participated in the training while they were closed for the season. Consequently, they did not have the opportunity to interact with customers or use any of the tips and strategies.

In terms of improving the physical environment, none of the businesses or organizations had yet to make any changes within the 2-week follow-up period. However, several respondents commented on plans to renovate the reception area to ensure that the front desk is located



immediately inside the entrance doors, rather than off to the side. Others mentioned plans to improve signage throughout their establishments, in order to make it easier to locate washrooms, displays, parking, exits, etc. Further, one respondent mentioned that their organization plans to designate a small room as a quiet area, in case customers become overwhelmed and would like to relax in a less crowded area. Another business was hoping to receive funding for renovations, which would make the main entrance more accessible.



7. Discussion

This evaluation examined the process of implementing the Blue Umbrella Program and the effectiveness of the training, in order to determine the appropriateness of the BU/DFC activities and tools, the extent to which knowledge, attitudes, skills and/or practices changed, the extent to which partnerships were formed, and the capacity of the local Alzheimer Societies to strengthen partnerships.

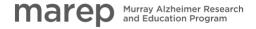
How have the knowledge, attitudes, skills, and/or practices of the involved businesses and social services changed as a result of engagement with the project?

The data suggests that the knowledge, attitudes, skills and practices of the involved businesses and social services changed as a result of engagement with the project. Participants enhanced their knowledge in several areas, including gaining a better understanding of dementia, enhancing their communicate skills, and developing practical strategies to support people living with dementia that may visit their organization or place of business. As an example, the tips and strategies for enhancing communication were particularly useful and gave participants greater confidence in their interactions with people living with dementia. Some participants found the strategies were applicable not only in the workplace but also in their personal lives, and could be applied when providing customer service to many different groups in the community—not just individuals living with dementia.

In what ways has the project built partnerships with the business/services community, and with people living with dementia and care partners?

During the course of this evaluation, the process of implementing the Blue umbrella Program enabled many partnerships to be formed with the business/services community. In fact, several local Societies became connected to organizations and businesses that they were previously not association with (e.g., municipal recreation department, legal services, and churches).

However, the most significant partnerships that were formed were with people living with dementia and their care partners. The Blue Umbrella Program provided opportunities to include people living with dementia as true partners in creating dementia-friendly communities. This had a significant impact on the knowledge acquisition of participants and success of the program. During the course of this evaluation, 27 volunteers were engaged in the



Blue Umbrella Program, including 10 people living with dementia and 17 care partners. As a result of the authentic partnerships formed between the local Societies and people living with dementia and care partners, they were also more likely to get involved in the Society in other ways.

How has the Alzheimer Society's capacity to partner with people living with dementia, care partners, and the business/service community been strengthened?

For all the local Alzheimer Societies participating in the pilot, the Blue Umbrella Program helped to strengthen their capacity to partner with people living with dementia, care partners, and businesses and organizations in the community. Several local Societies received grants for their program, while another was in the process of expanding the program to other communities within their region.

However, over the course of the pilot, both Alzheimer Society staff and training participants commented on the ability of the program to be sustained. Some participants felt that additional training would need to be held in order to address staff turnover and to ensure that new staff are continuously being trained. The topic of staff turnover within the businesses was also a concern to some local Societies, as significant staff resources are currently required to provide the training.

In order to sustain the program and its partnerships, in some cases, staff turned to technology to reduce the administrative load (i.e. creating online tools) and suggested other ways of using technology to sustain the program (i.e. online training). This would allow for a more efficient process, and a way to engage in more partnerships with the business/services community.

How appropriate have the BU/DFC activities and tools been? Are there other strategies that would deliver better results for the investment?

Overall, the Blue Umbrella Program was well received by the participants in this evaluation and the tools were found to be quite effective.

With respect to process, all three local Societies adopted a slightly different approach to program implementation. However, in all cases, the local advisory committees were instrumental in steering the direction of the program. They provided invaluable support, including recruiting businesses to participate in the program and volunteers to co-facilitate the



training. This evaluation found that forming an advisory committee was a critical first step for Societies in implementing the program.

One of the local Societies added a step to the process by asking residents to define what it means for them to "live well" in their community. The question was first asked at an open house for the Blue Umbrella Program, and was then asked of anyone who became involved with the program. The feedback helped to determine the values that create a high quality of life for residents in that particular community. The information was valuable as it could be applied to people living with dementia, who also wish to enjoy these same aspects in order to continue to "live well" in their community. This knowledge helped to shape the development of the program model in the community, along with the guidance from the local advisory committee.

Further, one of the local Societies developed additional tools (see Appendix H and Appendix I) to help establish a consistent process for becoming a supporter of the Blue Umbrella Program, and for on-boarding co-facilitators with lived experience. These new tools helped to ensure that a consistent approach was being followed within their community.

With respect to the training, participants found that the presentation was very informative, practical and valuable. For this reason, participants felt that the Blue Umbrella training should be offered to more businesses and organizations.

Further, this evaluation found that participants appreciated the opportunity to learn about dementia first-hand from a co-facilitator with lived experience. Having an individual speak candidly about their personal experience helped to "put a face" to dementia. Many participants mentioned that this was key in changing their attitudes and perspectives around dementia and as a result, they left the training with greater compassion and empathy.

In terms of timing, this evaluation found that the 2-week period between the training and the follow-up discussion with businesses did not provide staff with enough time to apply the tips and strategies from the training. In some cases, staff did not have enough time to develop a concrete implementation plan or make changes to their policies and practices before following up with the local Society and receiving the decal.

In addition, community members and businesses had different attitudes towards wearing the pin and displaying the decal. Not all people living with dementia elected to wear a pin. Similarly, some businesses had concerns over displaying the decal in their window. For one larger business, company policy would not permit staff to displaying a decal in the window.

The visits from "volunteer advisors" were effective in monitoring the strategies being used to support customers living with dementia. However, upon learning that an advisor might visit the establishment, some staff members were concerned about how their performance would be rated. Some staff was unclear about the purpose of the volunteer advisor visit and felt anxious about the idea of being evaluated. Some participants did not understand that the visit was not



meant to be a staff evaluation; rather, its purpose is to provide the business with feedback so staff can continue to develop the most appropriate and helpful dementia-friendly supports for their customers.

In terms of areas for improvement, participants suggested that the training could be more interactive and that the content—particularly the case scenarios—could be tailored to better meet the needs of the business or organization. This was particularly true for churches and not-for-profit organizations.



8. Limitations

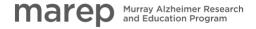
For this evaluation, the availability of data was one of several limitations. As each of the local Societies began piloting the project at different times, greater data was available from those societies that began earlier on. As a result, the perspective of this study is skewed, as data was not equally available from all of the pilot sites. Similarly, with only three sites actively delivering the Blue Umbrella Program, the scope of this evaluation was very narrow with respect to the type of community (i.e. rural vs. urban) and the diversity of the population (i.e. limited cultural diversity within the pilot communities).

The evaluation tools used in this study effectively captured how businesses and organizations responded to the training; however, the "Stories of Change" tool caused some confusion for participants. It is recommended that the term "Stories of Change" be changed to "Impact Stories", as a story does not necessarily have to incorporate a change to be considered impactful.

It is important to acknowledge that creating a dementia-friendly community does not happen overnight. It takes time for businesses and organizations to implement the dementia-friendly strategies and make changes to their policies and practices once they receive the Blue Umbrella training. For this reason, the timing and duration of the pilot was not sufficient to evaluate the impact from the business perspective. In addition, further research is recommended to determine the benefits of the Blue Umbrella Program for people living with dementia and care partners. In particular, focus groups should be conducted to examine in what ways, and to what extent, the lives of people living with dementia and care partners have changed as a result of their inclusion in the program. A deeper discussion around this topic would provide a better understanding of personal experiences with local businesses and organizations, and potential barriers and enablers to full participation in all aspects of community life.

Finally, a longer-term evaluation would be useful in determining how consistent the Blue Umbrella Program is with the needs and priorities of its target groups, as well as the policies of businesses, community partners, and funders. Additionally, it would help to examine the impact that the Blue Umbrella Program has had on the organizations that manage it, including the Alzheimer Society of Ontario and the local Alzheimer Society chapters. In terms of sustaining the program, it would be important to consider how the benefits produced by the Blue Umbrella Program will be maintained after the pilot.

While this particular evaluation examined the process of implementing the Blue Umbrella Program and the effectiveness of the training, further research is recommended that will expand the depth and breadth of the evaluation in order to determine the long-term impacts of the program.



9. Recommendations

Overall, the Blue Umbrella Program was successful in the three pilot communities. However, based on feedback from participants, follow-up discussions with businesses, reflections of Alzheimer Society staff, and observations of researchers, this evaluation recommends the following changes to the implementation process and training sessions, and makes suggestions for expanding the program scope.

Implementation Process

In terms of implementing the program, <u>developing a consistent process</u> is recommended to support local Societies in implementing the Blue Umbrella Program, and for on-boarding staff and co-facilitators with lived experience (see Appendix H & I for examples of implementation process from the Alzheimer Society Waterloo Wellington). This would help to ensure that a consistent approach is being followed within and across communities.

<u>Establishing a local advisory committee</u> is recommended as a critical first step in steering the direction of the program. In addition, local Society staff should also start by asking those involved in the program to define what it means for them to "live well" in their particular community. This knowledge would help to identify the values that contribute to a high quality of life, which should be reflected in the program model.

Further, once a business or organization receives the training, staff should be provided with more time to apply the tips and strategies before following-up with the local Society to receive their Blue Umbrella decal. Extending the 2-week follow-up period to at least 4-6 weeks is recommended. As a result, businesses and organizations would be able to use the time to develop a concrete dementia-friendly implementation strategy or action plan, which could then be shared and reviewed with local Society staff during the follow-up discussion. Further, it would provide more time for the business or organization to formulate questions based on their experiences with customers living with dementia, and would help the local Society to determine if further training is required and to deliver the additional training.

With respect to the Blue Umbrella pins and decals, <u>emphasizing that wearing the pin is an optional component of the program</u> is recommended. While individuals can choose to wear the pin as an opportunity to self-identify as an individual living with dementia, it is certainly not mandatory. Similarly, for businesses that had concerns with the decal, it would be important to explore another option—perhaps <u>designing a new pin for staff that wish to support the program</u> but are unable to display a decal in their establishment (e.g., perhaps the Dementia Friends pin could be incorporated).

In order to address feelings of anxiety regarding the Volunteer Advisor Evaluation, it would be important to emphasize to participants that the purpose of the visit is not meant to evaluate



staff; rather, the purpose is to provide the business with feedback so staff can continue to develop the most appropriate and helpful dementia-friendly supports for their customers.

<u>Changing the term "Volunteer Advisor Evaluation" to "Ambassador Visit"</u> is recommended, in order to make the encounter less intimidating for staff.

Once businesses and organizations have been trained and are designated as dementia-friendly establishments, including the names of the businesses in a "Dementia-Friendly Business Directory" is recommended. Developing this directory would benefit people living with dementia, as they would easily be able to identify those businesses and organizations that have been trained to provide a high level of customer service to them and their families. The directory would also benefit the businesses and organizations, as people living with dementia would be more likely to choose them over their competitors. Further, the directory would likely provide an incentive for new businesses to participate in the Blue Umbrella Program, in order to be recognized as an establishment that is welcoming and inclusive of all members of the community.

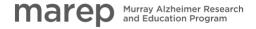
Blue Umbrella Training

In terms of the training, <u>involving a co-facilitator with lived experience throughout the entire training session</u> is recommended, as opposed to sharing their experience only at the beginning or end of the presentation. The individual living with dementia should be involved in delivering the training as much as possible, to the extent in which they are comfortable, in order to make the training more impactful.

In addition, <u>incorporating more opportunities for active participation in the training</u> is recommended, such as group discussions. If necessary, perhaps one of the video clips could be removed to provide more time for questions. By making the presentation more interactive, participants are likely to become more engaged in the session (e.g., consider using some of the principles of Dialogue Education).

An unintended impact of the program was the request for additional training and greater information on dementia. As such, <u>incorporating additional information about dementia in the training</u> is recommended. Perhaps additional handouts could be provided, such as the "10 warning signs of dementia".

In addition, presentation slides should be re-ordered to ensure that the "what is dementia?" slide is covered at the beginning of the session—currently, dementia is defined later in the presentation. Further, adding a new slide on "dementia-friendly language" is recommended to encourage participants to adopt appropriate terminology when referring to individuals living with dementia. The slide could provide examples of stigmatizing language (e.g., "dementia suffers") that should be replaced by dementia-friendly language (e.g., "people living with



dementia"). As a result, it is hoped that participants will leave the training with the ability to incorporate dementia-inclusive terminology in their vocabulary.

In some cases, training participants took brochures upon leaving the session and asked how they could become a volunteer with the Society. As such, <u>bringing a sign-up sheet for potential volunteers</u> is recommended for future sessions. This would help to recruit new volunteers and to build capacity for the program within local Societies.

Finally, in some cases, <u>tailoring the training to better fit the context of the organization</u> is recommended, particularly for churches and not-for-profit groups. Specific case scenarios should be derived from the initial assessment with partners, in order for local Society staff to develop tips and strategies that would best meet the needs of the organization in supporting their customers living with dementia.

Next Steps

With the success of the pilot, expanding the Blue Umbrella Program to additional communities across Ontario is recommended. In the future, it would be ideal to target the business and service sectors that were missed throughout the course of the pilot, including: Transportation, Finance, Restaurants, Hospitality, and Community Agency. It would be ideal if the Alzheimer Society of Ontario developed partnerships at a higher level (e.g., provincial organization; corporate head offices), making the process more efficient at the local level. By training businesses and organizations in these sectors, people living with dementia will be better able to participate fully in all aspects of community life.

In terms of sustaining the program, <u>creating online versions of the training components</u> is recommended. For example, a micro-site could be developed to host the presentation slides, video clips, and additional resources, as well as electronic versions of the post-training survey and follow-up documents for businesses. This would help to offset the significant staff resources currently required to deliver the training. Similarly, a "train-the-trainer" model could be explored as an opportunity to help address staff turnover in businesses.

In order to sustain the program and to continue building upon its success, <u>obtaining additional</u> <u>funding for dementia-friendly community initiatives</u> is required, as well as dedicated funds to supporting local Alzheimer Society staff. Currently, the Blue Umbrella Program is provided to businesses and organizations free of charge; however, significant staff and volunteer resources are required to coordinate the program, deliver the training, and follow-up with businesses. As it stands, it would be very difficult to sustain the program with current resources. With a growing need for dementia-friendly communities, it is hoped that additional funding will enable the Alzheimer Society of Ontario to expand the Blue Umbrella Program to communities across the province.



10. Conclusion

This evaluation has shown that to some extent all of the Blue Umbrella Program objectives are being met through the implementation process and the training itself.

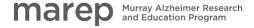
With regards to empowering people living with dementia, there are several opportunities for individuals to become involved with the Blue Umbrella Program, including: participating on the Blue Umbrella Advisory Committee, co-facilitating the training, and conducting Volunteer Advisor Evaluations. Engaging in the program in these ways provided an opportunity for individuals living with dementia to remain active and engaged in their communities, and in service/quality improvement.

Further, the Blue Umbrella Program provided education for businesses and organizations, which enhanced staff members' knowledge and awareness of dementia. The majority of staff appreciated the ability to learn about dementia first-hand from a co-facilitator with lived experience. This knowledge gave staff the confidence to provide appropriate dementia-friendly support to their customers.

Greater knowledge and awareness of dementia, combined with the opportunity to hear personal experiences from people living with dementia, resulted in a shift in attitudes around dementia; a novel perspective that goes against the stigma and misunderstanding of dementia that is commonly believed within society.

Finally, the Blue Umbrella Program allowed for the creation of new partnerships—and the strengthening of existing partnerships—with people living with dementia, care partners, and businesses and organizations. During the time of this evaluation, 27 volunteers were recruited, 53 businesses and organizations were trained, and 767 individuals were trained in the three pilot communities. These partnerships will help create more dementia-friendly communities.

In conclusion, the Blue Umbrella Program is creating a dementia-friendly business/service sector that is inclusive of people living with dementia. By making the community more dementia-friendly, its businesses, organizations, and community members will be better able to assist people living with dementia in the most appropriate and helpful ways. The Blue Umbrella Program is one dementia-friendly community initiative that is helping in this regard.



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Appendix A - Partner Needs Assessment

Pre-Training Partner Assessment Form	[Local Society logo and program logo]
Thank you for working with us as we strive to	make our community dementia friendly!
Business Name:	Main Contact:
There are three simple steps to becoming a	dementia friendly community:
 Identify what experiences your community Identify a number of scenarios. 	has had with people who are living with dementia.
 Identify what you would like to learn or how who have dementia. 	w we can make you more confident serving people
3. Call the Alzheimer Society so that we can "community" needs.	develop a customized 1-hour training to suit your
 Then we tailor information specific to item strategies re: orientation for all new staff, communication strategy tip sheets for all 	mer's and Dementia and communication strategies. Ins 1 and 2 above so that we can focus your policy changes, procedure changes, staff, promotion of your dementia friendly esite, and providing you with a dementia friendly
Other questions or comments?	
[Local Society contact information]	



Appendix B - Training Evaluation Questionnaire (Original Version)

Note: This template was used for all training session prior to April 1st 2017.

TRAINING EVALUATION QUESTIONNAIRE

	ank you for taking part in the Living W following questions. Your feedback i	Vell with Dementia training. Please take a few minutes to answer is important to us!
1.	Today's Date:	2. Location of training:

3. Please read the following and place a check beside the one that best describes you.

		Place a check ✓ beside the one that best describes you
a.	Business owner in [name of community]	
b.	A member of the [name of community]	
C.	Living with memory loss or dementia (e.g., Mild Cognitive Impairment, Alzheimer's disease, Vascular dementia, Lewy body dementia, etc.)	
d.	Supporting a person living with memory loss or dementia	
6.	Other: Please specify:	

4. Please rate the following aspects of this training using the scale provided:

		Strongly disagree	← →	Somewhat agree	← →	Strongly agree	Additional comments
a.	The pace of the session was just right	1	2	3	4	5	
b.	The volume of material presented was just right	1	2	3	4	5	
C.	The complexity of the material was just right	1	2	3	4	5	
d.	There were just enough opportunities to participate in the session	1	2	3	4	5	
e.	The handout was a valuable resource	1	2	3	4	5	
to	The language is easy understand and cessible	1	2	3	4	5	



5. Please rate the training facilitators using the scale provided:

The	facilitators	Strongly disagree	← →	Somewhat agree	← →	Strongly agree	Additional comments
a.	were effective in presenting the material	1	2	3	4	5	
b.	were knowledgeable in the subject matter	1	2	3	4	5	
C.	involved me in learning	1	2	3	4	5	
d.	managed time well	1	2	3	4	5	
e.	were able to clearly answer questions	1	2	3	4	5	

6. Please rate the value/helpfulness of the learning strategies used in this training using the scale provided:

	Not helpful at all	← →	Somewhat helpful	←→	Extremely helpful	Not Applicable	Additional comments
a. Use of video clips	1	2	3	4	5		
b. Group discussions	1	2	3	4	5		

7. Please read each of the following statements and indicate the extent to which you agree or disagree with each statement:

		Strongly disagree	← →	Somewhat agree	← →	Strongly agree	Additional comments
a.	The training met my expectations	1	2	3	4	5	
b.	The training will help me to perform my job better	1	2	3	4	5	
C.	The learning strategies used in this session helped me to understand the material	1	2	3	4	5	
d.	I feel I have learned something new from this session	1	2	3	4	5	
e.	I intend to apply what I learned today to my job	1	2	3	4	5	

8.	Identify two key learnings or skills that you intend to apply to your work?

9.	What were the elements of this training that you liked, and what do you think could be improved?
	Elements of the training that I liked:
	Elements of the training that could be improved:

10. Overall, how would you rate this training? (Please circle your response)

	Poor	Fair	Good	Very good	Excellent	Additional comments
Overall, the training was	1	2	3	4	5	

Appendix C - Training Evaluation Questionnaire (Revised Version)

Note: This template was used for all training sessions as of April 1st 2017.

TRAINING EVALUATION QUESTIONNAIRE

Thank you for taking part in the Blue Umbrella/ answer the following questions. Your feedback	Dementia Friendly training. Please take a few minutes to is important to us!		
1. Today's Date:	2. Location of training:		
3. Please read the following and place a check beside the one that best describes you.			

	Place a check ✓ beside the one that best describes you
a. A business owner	
b. A staff member	
c. A community member	
d. Living with memory loss or dementia (e.g., Mild Cognitive Impairment, Alzheimer's disease, vascular dementia, Lewy body dementia, etc.)	
e. Supporting a person living with memory loss or dementia	
f. Other: Please specify	

4. Prior to this session, my understanding of "dementia-friendly supports" was (please circ one):					
Very good	Good	Fair	No previous knowledge		

5. Please rate the following aspects of this training using the scale provided (please circle your answer):

	Strongly disagree	←→	Somewhat agree	← →	Strongly agree	Additional comments
I learned a great deal from this session	1	2	3	4	5	
b. The content presented was relevant to me and my needs in developing dementia friendly supports	1	2	3	4	5	
c. My expectations were met	1	2	3	4	5	
d. I will implement aspects of this training in my work/ everyday life	1	2	3	4	5	



6. What aspects of this train	ning will you	use in yo	ur work/ daily l	ife?		-
7. Please rate the following number):	aspects of the Strongly disagree	his trainin ← →	ng using the sca Somewhat agree	ale provid	ded (please o Strongly agree	circle a Additional comments
a. The pace of the session was just right	1	2	3	4	5	
b. The volume of material presented was just right	1	2	3	4	5	
c. The material was easy to understand	1	2	3	4	5	
d. There were enough opportunities to participate in the session	1	2	3	4	5	
e. The handout was a valuable resource	1	2	3	4	5	
f. The language was easy to understand and accessible	1	2	3	4	5	
8. What did you like about t	:his training?	•				
						
9. What can be improved in	n the training	 ?				
						
10. Other comments:						



Appendix D - Volunteer Advisor Evaluation

Volunteer Advisor Evaluation

Date			Reviewer's Name				
Business Name	Δ	Address		Phone		пе	Nature of Business
							busiliess
Did staff ask if people needed Yes	l assistance' □ No □	?					
Were staff patient with Yes □ Please Give €	No □	hers	?	,			
Did Check ✓ the ap			e following st and If not appli	_	ırk v	vith an x	
□ Look at the person □ Speak clearly □ Speak slowly in short specific sentence using familiar words Are there specific traits of the that make it difficult for the pedementia?	the for Ask at a Lim awa business rson with	item sim time	ake the person they are looking ple questions of estractions or mo om noise	ng one		person is Did the st the perso dementia talking Approach an open,	when gently with
(E.g. Very busy, physical eler layout, dynamics of staff). Please give examples.	nents,						
Did the person with dementia good comfort level in the envi		trai Yes	urther staff ning required? s □ No □ at aspects?				
Other Comments			Feedbac	ck/solutio	on/s	uggestio	ns



Appendix E – Partner Discussion Summary Sheet

Summary Sheet – Partner Discussion

Name of business:
Summary of themes/issues
2. Stories told
3. AS volunteer/staff's observations/insights into the discussion
4. Recommendations



Appendix F - Story of Change Template

STORY OF CHANGE TEMPLATE

[This is to be handed out to participants]

A story of change is about sharing your experience in being a part of Blue Umbrella/ Dementia-Friendly Communities work. It can be how you now feel more confident going out in the community, about a specific experience with others, how this work has changed your perceptions, the way you do your job etc.

We will be gathering these stories and hope to share them across the province! They will help us to understand how this work is having an impact and how we can improve.

[Space provided to share story of change]						



Appendix G – Communication Tips



Dementia Friendly Communities Communication Tips

People living with dementia may experience changes with their memory, communication, and the ability to perform day-to-day activities. Each person living with dementia will have different needs.

- ✓ Introduce yourself
- ✓ Be patient and show respect
- Speak clearly and avoid speaking too quickly
- ✓ Use short, simple sentences
- Offer to help them find what they are looking for
- Ask questions with 1 or 2 options instead of asking open-ended questions (e.g., would you like to pay with cash or credit?)
- Be mindful of your tone and facial expressions
- ✓ Reduce distractions
- ✓ Listen give your undivided attention

For more information:

[local society URL]



Dementia Friendly Communities Communication Tips

People living with dementia may experience changes with their memory, communication, and the ability to perform day-to-day activities. Each person living with dementia will have different needs.

- ✓ Introduce yourself
- ✓ Be patient and show respect
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- Be mindful of your tone and facial expressions
- ✓ Reduce distractions
- ✓ Listen give your undivided attention

For more information:

[local society URL]

(Created by the Alzheimer Society Waterloo Wellington in partnership with the Waterloo Wellington Dementia Advisory Group and the Murray Alzheimer Research and Education Program, January 2016)

Appendix H – Process for a Community Location to Become a Supporter in the Blue Umbrella Program

Dementia-Friendly Communities:

Process for a Community Location to Become a Supporter in the Blue Umbrella Program

(Created by the Alzheimer Society of Waterloo Wellington, May 2017)

When [local society] receives an education or training request for the Blue Umbrella Program, the following process will be observed:

- Initial Request/Conversation:
 - Public Education Coordinator will take request. During the call, understand the business and training interest, and establish the percentage of people in the organization that need to be trained to have an impact (our goal is 75% of staff; however each request will be considered on an individual basis and this is a guideline only). Provide an overview of the Blue Umbrella training program, and please include some information on how "this program is currently offered at no charge, however donations are always welcome"
 - Determine if there is an opportunity to "buddy up" with another group for training if the amount of staff could be too small for an individual education session.
 - Try to get specific case examples at the time of initial conversation to tailor training
 - Set potential date and location, ensuring requestor knows confirmation is pending the availability of a co-facilitator. Organize a person living with dementia to co-facilitate, and transportation if needed. When date and time is confirmed, inform MAREP and request someone to attend for evaluation.
 - Sort out details of tech, seating, timing etc. Check on parking and arrange parking for up to 4, to be confirmed. If parking is not free, ask for the cost of it to be covered.
 - o Add all details of the training request to the master excel spread sheet.
- Before Training Session:
 - Send out slides to be pre-printed by business/location 7 days prior to training, along with a reminder confirmation. NOTE: you may need to personalize the case examples.
- Provide Training onsite:
 - Ensure data from the training is documented on the excel spread sheet on SharePoint.
- Following Training:
 - o Follow up 2 to 4 weeks after training. Follow up by email and provide decals by mail. Also, add stickers (Dementia Friendly flowers) if



- appropriate for the business to have at tills. Ensure the appropriate paperwork has been sent ahead (re: impact stories), and when returned forwarded to MAREP.
- If appropriate to send an "ambassador" (formerly secret shopper) arrange for one approximately two weeks after the follow up contact.
 Ensure if there is a cost to follow up (i.e. attending a show) it is covered by the organization being trained. Ensure the appropriate paperwork has been sent to the ambassador and collected afterwards. This paperwork needs to be forwarded to MAREP.
- Send an email to the organization, if an ambassador has been out to visit, letting them know the ambassador has visited, along with an constructive feedback applicable.
- Ensure follow up data documented in the excel spreadsheet on SharePoint.
- Work with [local society staff] to add the organizations name to our website under DFC trained.



Appendix I – Process for On-Boarding a Co-Facilitator with Lived Experience for the Blue Umbrella Program

Dementia-Friendly Communities:
Process for On-Boarding a Co-Facilitator with Lived Experience for the Blue
Umbrella Program
(Created by the Alzheimer Society of Waterloo Wellington, May 2017)

When a person living with dementia has expressed interest in becoming a cofacilitator with lived experience for the Blue Umbrella Program, [local society] will observe the following process:

- Public Education Coordinator and/or current co-facilitator with lived experience will talk with the interested person about the program and the co-facilitator role. Discuss the person's availability for presentations, contact information and transportation requirements.
- Arrange a time to review the Blue Umbrella training presentation in detail, and to receive a Blue Umbrella t-shirt and pin.
- Arrange a time for the person to observe a booked presentation, and see a fellow co-facilitator present. De-brief after this observation to see if there are any questions or concerns, and to see which sections and presentation style the individual is most comfortable with.
- Confirm availability, transportation, etc. and next steps.

