

Empowering Dementia Friendly Communities Hamilton, Haldimand

Dementia Friendly Communities Education Program Evaluation

Final Report Executive Summary

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Executive Summary

The *Empowering Dementia Friendly Communities in Hamilton and Haldimand* project proposes to enable the Hamilton Council on Aging (HCoA) to continue and expand the development of dementia friendly communities in Hamilton and Haldimand. The Empowering Dementia-Friendly Communities Hamilton, Haldimand project is a collaborative initiative, led by the Hamilton Council on Aging (HCoA), citizens and a multi-disciplinary team of organizations including persons living with dementia, the Alzheimer Society of Brant, Haldimand Norfolk, and Hamilton Halton, the GERAS Centre for Aging Research, the Regional Geriatric Program central, McMaster University, Haldimand-Norfolk Community Senior Support Services, Hamilton Health Sciences, Haldimand War Memorial Hospital and the Age-Friendly Hamilton Collaborative Governance Committee. This project is funded by the Public Health Agency of Canada. GERAS' role in this initiative is to develop and implement an evaluation of the Dementia Friendly Communities project.

This project proposes to integrate a Dementia Friendly Community Plan with Hamilton's municipal Plan for an Age Friendly City (2021-2026). Building on the findings of an extensive community consultation to better understand the experiences, challenges and ideas of persons affected by dementia and leveraging the universally beneficial outcomes and influence of Age Friendly Hamilton, this project aims to:

1. Optimize the wellbeing of people living with dementia and/or their family/friend care partners.
2. Promote awareness of dementia and its risk factors by supporting innovative approaches that tackle stigma and promote compassion and support.
3. Undertake intervention research to assess the effectiveness of the program or initiative and promote/apply this knowledge.

The initial community consultation for this project,¹ revealed the need for further community education to increase awareness about dementia and the stigma that results when communities are not dementia friendly. A Dementia Friendly Communities education program was developed with aim of increasing knowledge and understanding of: Dementia Friendly Community (what it is), dementia, the experience of living with dementia, stigma, and how to create a Dementia Friendly Community. The program consists of a core curriculum, workbook, and supportive learning/ resource tools. The following groups were targeted for this education program: public service sector (community organizations, libraries, museums); retail (grocery, clothing, 'for-profit' businesses); hospitality industry (restaurants); and, faith groups; the program was also open to any interested individuals or organizations. The program was launched in September 2021, and delivered virtually in keeping with COVID-19 pandemic protocols, though as pandemic restrictions eased, in-person education workshops were offered.

This report describes the methods and results of an evaluation of the Dementia Friendly Communities education program.

¹ Hamilton Council on Aging. What We Heard Report. Empowering Dementia-Friendly Communities Project Hamilton, Haldimand. June 2021. Available at: https://coahamilton.ca/wp-content/uploads/2021/06/HCOA_WWH_EN_June2021.pdf

Evaluation Objectives: The objectives of the evaluation of the education program were to:

- i) Describe the delivery of the Dementia Friendly Communities education workshop;
- ii) Describe participant reactions to the Dementia Friendly Communities education workshop;
- iii) Describe the ways in which new knowledge from the Dementia Friendly Communities education workshop was applied by participants; and,
- iv) Describe impacts associated with participation in the Dementia Friendly Communities education workshop.

Evaluation Approach: The evaluation plan was based on the program logic model for this education program and was developed consistent with Kirkpatrick's evaluation model, a frequently used framework for evaluating education/ training programs, focusing on participants reaction (satisfaction) with the education, self-reported changes in knowledge and attitudes, and behaviour as a result of the education, and outcomes (results) associated with changes associated with the education.

Design and Sources of Information: A survey methodology, with tracking of key program outputs, was used to meet the objectives of this evaluation, using the following sources of information.

- **Tracking of Key Program Outputs:** To describe the implementation of this program, information about key program activities were tracked including delivery format (online, virtual), attendance, location (Hamilton, Haldimand), as tracked using an excel spreadsheet completed by the Education Coordinator.
- **Education Workshop Satisfaction Survey:** To obtain participant feedback on the program a satisfaction survey was administered at the end of the workshop. Satisfaction surveys were completed by 58% (110 /191) of workshop participants.
- **Workshop Follow-up Survey:** To assess application of new learning/ actions taken to make their workplace/ community more dementia friendly, all workshop participants were invited to complete an online (www.surveymonkey.com) survey three months following workshop completion. The follow-up survey was completed by 25% (36/145) of workshop participants.

Research Ethics Board Approval: As the objectives of this evaluation are considered quality improvement, research ethics board approval was not required. A waiver for approval was received the Hamilton Integrated Research Ethics Board (HiREB), McMaster University.

Data Collection Analysis: Survey data were analyzed using SPSS 27.0. (Chicago, IL: SPSS Inc, 2021). Frequencies were generated for all numerical survey data. Analysis of open-ended survey questions and interviews were consistent with recommended practices for qualitative evaluation data.

Key findings

Evaluation Objective I: Describe the delivery of the Dementia Friendly Communities education workshop

Workshop Delivery: In total, 26 education workshops have been delivered between September 23, 2021 and February 27, 2023; this includes three pilot session workshops (September 23, 28, 2021, and February 15, 2022). A total of 277 individuals registered to participate in the workshops; there were a total of 229 participants, representing 83% of those who registered. The majority of the workshops (85%: N = 22) were delivered via video-conferencing, three in-person, and one via teleconferencing. Across 25 of the workshops for which data is available, 168 people who attended were from Hamilton, 23 from Haldimand, and 18 from other locales. Over half of the education program participants were from the public service sector (representing municipal services, community and social services), less than 3% were from the retail or hospitality sector or faith groups. After March 1, 2023, eight workshops are scheduled with various senior, long-term care (Family Councils), community groups. Interest has been expressed for the delivery of more workshops beyond the project end date (March 31, 2023).

Evaluation Objective II: Describe participant reactions to the Dementia Friendly Communities education workshop

Perceptions of the Workshop: The education workshops were very well received; satisfaction survey results revealed that the majority of respondents:

- perceived the workshop to be “very good” (27.3%) or “excellent” (56.4%).
- were satisfied (sum of somewhat satisfied and very satisfied ratings) with the topics covered in the workshop (88%), the format (online/ in-person; 89%), and the education workbook (89%); in all cases the majority of respondents provided ratings of “very satisfied”.
- Agreed that the workshop was worth their time (87%) and they would recommend the workshop to others (93%).

It was really well organized. Enjoyed the presentation, discussion and opportunity to ask questions.

[Presenters] provided a amazing presentation. However, [Presenter’s] first hand experience, her ability to share her own journey was extremely thought provoking and will change my practice moving forward! Thank you for all that you are both doing!

Participants expressed satisfaction with the presentation and the content covered and expressed appreciation for the sharing of experiences from a person living with dementia.

Perceptions of Program Resources: The majority of respondents:

- rated the program resources (tip/ information sheets, additional resources) as “very” (54%) or “extremely” (40%) helpful.
- agreed that the program materials will help them apply what they learned in the program (88%) and that workbook was easily understandable (92%).

Having resources consolidated is very helpful and the variety of resources (videos, lists, etc.) is valuable for different individuals and situations

I really appreciate the quick tip sheets. They would be a great resource to post in common areas (drivers lounge).

Comments made about the program resources reflected the respondents liked them, thought they were useful, and intended to share them.

Would love more time focused on concrete ways to improve our environment to make it more dementia friendly.

Great interest in practical strategies, so more time to discuss that would be beneficial.

For more engagement - possible use of zoom polls about myths about dementia.

Suggestions for Improvements: Related to the content of the program, some respondents expressed an interest in learning more about specific dementia friendly community strategies, and for more opportunities for discussion and interaction.

Final comments made by workshop satisfaction survey respondents reflected their satisfaction with the workshop, willingness to recommend it to others, gratitude for having participated in it, the importance of this topic, and the value of having a person with lived experience as a co-presenter.

This workshop was a great eye opener, I would recommend this course to many more groups or individuals.

I think the stories shared by people living with dementia is very eye opening.

Thank you for this exceptionally important workshop.

Great workshop!! I love the focus on person centered approaches and the lived experience to build empathy and understanding as to WHY this is important.

Thank you! I feel encouraged not only for myself but for future generations.

Evaluation Objective III: Describe the ways in which new knowledge from the Dementia Friendly Communities education workshop was applied by participants.

Impact on Intentions to Implement and Self-Reported Implementation of Dementia Friendly

Actions: At the time of the workshop, the majority of respondents:

- agreed that they intended to apply what they learned in the workshop to their life or work (91%).
- reported that they planned to offer support to (87%) and be more patient with persons living with dementia (94%), encourage others to become dementia friendly (80%), be aware of personal negative biases and attitudes (92%), and seek out more information about dementia and how to support people living with dementia (83%); at follow-up, a high percentage of respondents (72% - 83%) indicated that they were able to do so following the workshop

While roughly three-quarters of respondents indicated at the time of the workshop that they intended to make their workplace/ community more dementia friendly (76%) and would make sure others are educated about effective communication strategies for use with people living with dementia (72%), at follow-up a little over a quarter of respondents indicated that they were able to do this following the workshop (42%, respectively). At the time of the workshop, a lower

percentage of respondents indicated that they intended to adapt or put more services in place for persons with dementia (51%) and make environmental changes in their organization or public space (43%), and at follow-up, even fewer indicated that they were able to do this (31%, and 25%, respectively).

Ongoing education and awareness for staff and members of our organization

Continue ongoing conversation as part of development of customer service and customer experience strategies. Consider which metrics or indicators we might track to help us understand the quality of our service from a dementia-inclusive perspective.

We are getting a new physical space that we plan on designing using dementia friendly design principles and consult individuals living with dementia in the community about the design and purpose of the space.

Immediately following the workshop, some respondents identified other actions/ things (then listed above) they planned to do to help make their workplace / community more dementia friendly as related to sharing information with and educating others, adding additional supports to existing services for persons living with dementia or creating new services and gathering input of persons with lived experience when making environmental changes.

At follow-up, respondents indicated that they have altered their communication to provide more simple instructions, slow down the speed of their conversations (voice mail messages), and speak directly to persons living with dementia rather than their caregivers, involve people living with dementia in activities, reinforced the need to support the autonomy of people living with dementia, adapted how they work with people living with dementia, and shared the information received at the workshop.

Re-recorded voice mail message and after-hours message to slow down the speed of my voice.

Involving the people living with dementia in different activities with less assistance from the caregivers. Giving them simpler instructions when it comes to giving them activities to do. Respecting their privacy.

I had conversations with family members about increasing the autonomy of their loved ones. They tend to want to direct all things and I can see now how deflating can this be. I try to model this by giving the patient more choice and include them in decisions. And taking the advice I learned in the workshop - where appropriate, I don't talk to the caregiver or spouse - I direct my questions to the person with dementia. You learn so much doing this! I've talked to my coworkers about this.

Role of Supportive Resources in Implementation: Consistent with satisfaction survey respondents ratings of satisfaction with these resources, the majority of follow-up survey respondents rated the workshop (72%), education workbook (67%) and supportive resources (79%) as “very” or “extremely” useful as they applied what they learned in this program.

Evaluation Objective IV: Describe impacts associated with participation in the Dementia Friendly Communities education workshop.

Impact on Knowledge Acquisition: The majority of satisfaction survey respondents: (84%) agreed that they learned new things applicable to their life or work. The majority of respondents (>65%) reported that compared to their knowledge prior to completing the workshop, they were now (as a result of the program):

- more knowledgeable about dementia (71%),

- stigma (68%),
- dementia friendly communities (81%),
- social (66%) and environmental (70%) factors that create stigma, and how to address these factors (73%) and,
- how to make the community more dementia friendly (77%).

Impact on Capacity Building to Support Dementia Friendly Communities: At follow-up, the majority of survey respondents (>61%) reported that as a result of participating in the workshop they are now more effective at:

- communicating with persons living with dementia (75%),
- noticing things that may not be dementia friendly (75%),
- providing support to persons living with dementia (64%), and
- providing information to others about how to be dementia friendly (61%).

A little less than half of the respondents reported that they were now more effective at creating a dementia friendly workplace or community (47%).

Conclusions: Based on the findings of this evaluation, the following conclusions can be made:

- The Dementia Friendly Communities education program was well received by participants; the content and supportive resources (workbook, tip/ information sheets, additional resources) were highly valued and praised. No negative or critical feedback was obtained on the workshop or resources. A key factor contributing to satisfaction with the program appears to be the inclusion of a person living with dementia as a co-presenter. Survey respondents commented on the value of hearing from a person with lived experiences, referencing how thought provoking, powerful, and impactful this was. The decision to include a person with lived experience as a co-presenter further reinforced the project's focus on creating dementia friendly communities through the inclusion and engagement of persons living with dementia. Generally, few suggestions for improving the program were provided; those identified focused on learning more strategies for developing dementia friendly communities and more opportunities for discussion and interaction. These suggestions may require the workshop to longer in length; feedback received when the workshop was two hours in length suggested that shorter education sessions were preferred. Balancing time constraints and desire for more content and discussion may be challenging, but perhaps worth exploring as discussion and engagement among participants may facilitate the application of new learnings/ implement dementia friendly strategies. The majority of program participants were from Hamilton; very few (N = 23) were from Haldimand. Greater, and perhaps, more targeted promotion is needed in rural areas to increase participation.
- The education program was able to achieve its goal of increasing awareness and knowledge about dementia, stigma, and how to reduce stigma and create dementia friendly communities. Following the workshop participants reported an increase in knowledge in all of these areas and at follow-up participants identified increased capacity in their ability to communicate with and support persons living with dementia, to notice things that are not dementia friendly, and providing information to others about dementia friendliness.

- At the time of the workshop a high percentage (80% - 94%) of the participants had intentions to implement dementia friendly strategies at a personal level that they had agency over (e.g., offering support to persons living with dementia, encouraging others to be dementia friendly, being more patient, and being aware of personal biases) and at follow-up many reported being able to do so (72% - 83%). Fewer intended (43% - 51%) and were able to implement strategies (25% - 31%) at an organization level (adapt services, make environmental changes); this is reflected in the finding that 50% of participants did not perceive a change in the level of dementia friendliness within their organization. This likely reflects the decision-making capacity that participants have within their organization; the majority of participants reported that they have minimal capacity to make workplace changes. This suggests that in order to affect change at organizational levels, it might be prudent to also target the program to organization leaders – the decision-makers and policy makers. In identifying needed resources or supports to facilitate the creation of dementia friendly workplaces, participants identified the need for more education, guidance on policy and program development and more time allotted for interactions with persons living with dementia as part of their workload; these needs are best supported with awareness raising and ‘buy in’ from management.

Limitations: There are several limitations to this evaluation. Despite the use of best practices for survey administration, response rates to both the workshop satisfaction survey and the follow-up were very low (58% and 25%, respectively), impacting the generalizability of the findings. The low survey response rates made it difficult to analyze the findings by community and target group; larger sample sizes would be helpful to better understand differences in results based on community and target group and would assist in better identifying needs to support the implementation of dementia friendly strategies. The low response rate for the follow-up survey may be because the education program was brief, endearing less attachment than, if for example, the program had been longer and deeper relationships developed with educators and fellow participants. Future evaluations of the program may want to consider the use of incentives to increase the response rate (e.g., use of prizes/ gift cards, draws). Changes in knowledge and behaviour as a result of this program are based on participant self-report and use of post-pre comparisons (post-program assessed changes from pre-program). Alternatively, pre-post methods (e.g., knowledge quizzes before and after the workshop) could be employed; this may require some changes to the processes used to register participants (e.g., submission of email addresses prior to the workshop to access a pre-test) or changes to the program length to include time for pre- and post-knowledge tests within the agenda. More creative methods may be needed to measure pre-post changes in the implementation of dementia friendly strategies.