

## **Empowering Dementia Friendly Communities Hamilton, Haldimand**

# **Evaluation of the Lived Experience Leadership Teams**

### **Final Report Executive Summary**

**March 2, 2023**

**Prepared by the GERAS Centre for Aging Research  
George Ioannidis, PhD  
Loretta M. Hillier, MA**

**To request a copy of the full report please contact:**

Hamilton Council on Aging: [info@hamiltoncoa.com](mailto:info@hamiltoncoa.com) or call (905)777-3837 ext. 12434  
Geras Centre for Aging Research: Dr. George Ioannidis [ioannidis@HHSC.CA](mailto:ioannidis@HHSC.CA) or  
call (905) 521-2100 ext. 12437

*Financial contribution from*



Public Health      Agence de la santé  
Agency of Canada      publique du Canada

## 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.

One of the deliverables for this project was the development and implementation of two action plans aimed at creating dementia friendly communities, one in based in Hamilton and the other in Haldimand County. Originally the plan was to procure Request for Proposals from community organizations and agencies to development and implement these action plans. However, a key learning from the community consultation process, implemented in 2020 as part of the Empowering Dementia-Friendly Communities (DFC) Hamilton, Haldimand project, was the need to empower persons living with dementia to be engaged to enable community change. To this end, the first two action plans stemming from the consultation process was the development of Lived Experience Leadership Teams within each community (Hamilton: Dementia Friends in Our Community; Haldimand: Memory Inclusive Communities for Everyone, MICE), led by and consisting of persons living with dementia, supported by the Empowering Dementia Friendly Community Hamilton, Haldimand project team (Stewardship Group members and project staff, including a Project Coordinator dedicated to supporting the Lived Experience Leadership Teams). These teams were tasked with developing and implementing action plans consistent with the what was proposed for the community-based action plans that were originally to be proposed by community organizations and agencies. Two members of Stewardship Group who live with dementia and who are members of the Dementia Friends in Our Community team served as team facilitators for both teams to assist the teams to achieve their mandates. For their project, the Hamilton team elected to create and distribute a quarterly newsletter with articles

written by team members on various topics related to living with dementia. The Haldimand team elected to create an art contest to print a mural related to dementia to be displayed in the community and held a community festival to celebrate the unveiling of the mural.

This report describes the methods and results of an evaluation of the Lived Experience Leadership Teams and their perspectives on their team projects.

**Evaluation Objectives:** The objectives of this evaluation were to:

- i) Describe the development and implementation of the lived experience leadership teams;
- ii) Describe leadership team member perspectives on their involvement in this initiative and the team projects;
- iii) Describe the team action projects; and,
- iv) Describe outcomes associated with the lived experience leadership teams and team projects: impacts at participant, partner and staff, and community levels

**Evaluation Approach:** A mixed methods (quantitative, qualitative) approach was used to achieve the objectives of this evaluation, specifically, to describe the development and implementation of the lived experience leadership teams (formative evaluation) and to evaluate the outcomes associated with leadership teams (summative evaluation). The evaluation plan was guided by the program logic model for the leadership teams and the CHOICE community empowerment and equity framework.<sup>1</sup>

**Sources of Information:** The following sources of information were used in this evaluation.

- **Document Review**, including relevant team documents (terms of reference, staff notes, recruitment ads, meeting agendas, PowerPoint presentations, and minutes, promotional materials), audio files (radio interviews), and videos (recorded Zoom team meetings) was undertaken to describe the development of the leadership teams and the implementation of their projects.
- **Survey of Lived Experience Leadership Team Members** (N = 6/6; 100%) obtained team member perceptions on being a member of the leadership team and to assess outcomes associated with team membership.
- **Interviews with Members of the Lived Experience Leadership Teams** conducted at two time points (July 2022, N = 5; Fall 2022/ Winter 2023, N = 6) gathered more in-depth information about their perceptions of being a member of the team and the projects developed and implemented by their team.
- **Key Informant Interviews** (N = 3) gathered in-depth information about the development and implementation of the Lived Experience Leadership Teams and their action plans (projects) from the perspective of those who supported the teams.
- **Tracking of Key Program Outputs**, as conducted by program staff, was used to describe the implementation of the leadership teams and their projects.

---

<sup>1</sup> Rifkin, S.B. (2003). A Framework Linking Community Empowerment and Health Equity: It is a Matter of CHOICE. *Journal of Health, Population, and Nutrition*, 21(3), 168-180.

**Key Outcome Indicators:** As assessed across the sources of information for the evaluation, the key outcome indicators were:

- Detailed description of the lived experience leadership teams (formation, activities, functioning, resources and supports);
- Identification of key lessons learned in the development and implementation of the lived experience leadership teams and development and implementation of the team projects;
- Team member empowerment; and,
- Team member well-being as a result of being a member of the leadership team.

**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 28.0. (Chicago, IL: SPSS Inc, 2022). 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. A descriptive qualitative content analysis was used to understand the experiences and perceptions of persons interviewed for this evaluation (leadership team members, key informants).<sup>2</sup>

## Key findings

### Evaluation Objective I: Describe the development and implementation of the lived experience leadership teams

This report describes the supports available to the leadership teams (Team facilitators, Project Manager, Project Coordinator), team member recruitment and the role that leadership team members played on the team, how each of the teams were similar and different and the role of the Age Friendly Plan and geography (urban, rural) in the work of the teams.

#### Key Informant perspectives

**Factors facilitating the development and implementation of the leadership teams:** Key informants identified a number of factors that they perceived were instrumental to enabling the teams:

- Project coordinator role;
- Community engagement;
- Provision of clear and accessible information;
- Team member freedom to choose the project focus;
- Funding and resource support; and,
- Supportive governance structure.

*“I think the project coordinator played a huge role in terms of gaps that needed to be filled and provide the kind of support needed that was flexible and accommodating to the individuals and the teams as a whole. I think that’s really important.”*

*“So, originally, we had the Steering Committee, it automatically presumed a Steering Committee is really making those decisions right, its top down. And so Steering Committee steers the project. Stewardship group stewards the project. So, our change to Stewardship Group meant that the stewardship’s group role was to kind of support and enable the how, the ecosystem in which this work was happening. I think that’s a very different structure.”*

---

<sup>2</sup> Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33, 77-84.

**Challenges experienced:** Key informants generally noted that the teams faced few challenges in completing their projects. Although problematic issues arose, with brainstorming, these were generally resolved. Identified challenges included:

- Unclear understanding of the role of the teams within the context of the project as a whole; and,
- Unclear understanding of the purpose of the teams (initially).

*“The only thing that I’m never too sure about is that they [leadership team members] really understand that they’re part of this bigger project. I wonder, they had questions and I don’t think they really understand what the Stewardship team is. I think they [the Haldimand team] know there’s a Hamilton team, but I think that comes with repetition, because it can be hard to kind of wrap your head around that.... They didn’t know even who they were representing, when they were starting to approach people for the festival.... Where are we coming from? To make sure it came out legitimate, that they are part of a bigger project.”*

*“Basically, trying to figure out first of all why they established, what was their goal and what had they signed up for essentially.... They really didn’t know themselves I think why they were there. That was a little bit of a struggle.”*

**Team Access to Needed Information, Resources, and Supports:** Key informants believed that

*“I think when it comes to resources, they just had so much support either from the community members. They did have some funding allocated so when there’s money that helps a lot.... But resources and having everything that they needed to be successful, I do think that they had everything at their disposal for that.”*

leadership team members had access to all of the needed information, resources, and supports to complete their projects. Access to funding ensured that individual team member needs were met, with for example, WIFI enabled iPads to access the internet in order to attend virtual meetings, and travel accommodations to attend in-person events. Where funding was not available, attempts were made to secure in-kind resources from partners or seek local funding support as was the case with the MICE festival. Attempts were made to identify any personal

barriers that team members had that threatened their ability to participate in team activities so that these could be problem-solved (e.g., use of voice to text aids for a team member having difficulty with writing). Generally, the Project Coordinator’s role was support the teams to complete the projects.

**Key Lessons Learned in Development and Implementation of the Leadership Teams:**

identified key lessons can serve to inform project initiatives moving forward and that can serve as advice to others wanting to create leadership teams:

- Provide project coordination and support;
- Have appropriate governance structures and policies in place;
- Become a learning organization;

*“I would advise them to consider the structure to see if they were well positioned to the purpose of the leadership team, that’s a really important one. So, what policies would affect the leadership team? What resources do you have available?”*

*“I think just knowing that its going to probably take time, and as with any team I think, its really making sure at the beginning building that rapport within the team members. I think once they get comfortable with one another, it will just come out.”*

- Develop relational accountability<sup>3</sup>;
- Accept that this type of work takes time; and,
- Communicate clearly the purpose of the team as part of the recruitment process.

***Understanding of the Leadership Teams Within the Context of a Community Empowerment/Engagement Framework: The CHOICE Framework:*** The CHOICE framework was used in this evaluation to better understand how community (persons living with dementia) empowerment in this project affected project outcomes. Based on evidence from the various sources of information about the leadership teams from the evaluation, it was evident that framework components (capacity building, human rights, institutional accountability, contribution, and enabling environment) played a significant role in affecting how the teams functioned and their ability to complete their projects. There is, however, less clear evidence to support the organizational sustainability of the teams and their projects. A key factor impacting sustainability is the fact that this project was funded by an external agency for a limited time; without ongoing funding or other sustainability mechanisms continuing the work of the leadership teams will be difficult. While attempts are being made to secure more funding through grant funding, it is not clear how this will impact the existing teams and projects.

## **Evaluation Objective II: Describe leadership team member perspectives on their involvement in this initiative and the team projects**

***Personal Goals for Team Involvement:*** Leadership team members identified a number of reasons, or personal goals, for joining the teams:

- Meaningful engagement;
- Test ability to function in a group setting; and,
- Change community perceptions about dementia.

All of interviewed leadership team members believed that they were able to achieve these goals through their involvement with the team.

*“I was looking for something to do but also something worthwhile. I mean there were a lot of make work projects I could have gotten involved in, but they didn’t really appeal.”*

*“It was a good trial run for me to get out in the world again in a way that I would have lots of safety nets around me ... to be a bit of a test of: ‘Can I do this? Can I still function in this kind of structured environment.’”*

***Satisfaction with Team Involvement:*** All interviewed team members reported that they were very satisfied with their involvement on the team, specifically noting their satisfaction with their project plans, and how the teams functioned, particularly the encouraging and inclusionary nature of the teams. Surveyed team members were asked to rate the extent to which they agreed or disagreed with various statements related specifically to the terms of reference (guidelines) established for the teams (for the teams). The majority of respondents (>83%) agreed that team

---

<sup>3</sup> Relational accountability is an emerging concept that is based on social relationships in which shared values and moral obligations shape mutual expectations and strengthen continued involvement, or sense of belonging, in a team partnership. Traditional, formal and highly structured accountability processes are viewed as impeding the collaborative work of partnerships, particularly when there are hierarchical power differentials. Stewart et al. We hold ourselves accountable: A relational view of team accountability. *Journal of Business Ethics*. 2021, Nov 18; 1-22.

members respected different perspectives (83%), listened without interruption (83%) and were understanding with each other (100%). Fewer, but still the majority of respondents (67%) agreed that team members respected each other's privacy. Similarly, team members were asked to rate various aspects of their interaction within the team. All of the respondents agreed that they were able to speak freely in their meetings and the majority (67%) agreed that they felt listened to and that the work of the team will improve community attitudes about dementia. Fewer respondents (33%) agreed that they learned new things about being part of a team or feel better able to stand up for the rights of people living with dementia as result of being part of the leadership team.

*"It is the first time since my diagnosis I have felt inclusion and self worth. It is also an important project. Memory+ diagnosis can be difficult to understand if you don't have any connections to these disease progressions. People can become invisible, a person to hide. Other diseases may get "championed", they are warriors. So are we, and this is an awesome opportunity for a voice. It is the first time in years I was welcomed and involved in a project. I love the experience. Otherwise, I am alone and don't do anything. Its hard to find a place where people understand you."*

**Factors that Facilitated Team Member Participation and Completion of Team Projects:**

Leadership team members identified a number of factors that facilitated, or enabled, them to complete their projects:

*"We seemed to, with our meetings and all that, on a regular basis, they seemed to go okay. We all got along well and worked together."*

*"I think the common goal of trying to dispel the myths about living with dementia and offering hope was a big motivator."*

- Dedicated team coordinator;
- Team members worked well together;
- Common vision and shared commitment;
- Taking time to team build;
- Access to funding;
- Identifying the project focus; and,
- Team members having known each other previously.

**Challenges experienced:** Lived experience leadership team members identified a number of challenges, or barriers to project completion; some of these changes were common across both teams, while others were project specific:

**Team-wide challenges:**

- Limited team member recruitment due to stigma;
- Initial lack of clear communication about the project intent; and,
- Limited engagement of some team members.

*I found [team member recruitment] very challenging even though we were able to get people because people are still hiding from the stigma. Still, some of them say: 'we'll do what it takes but we don't want our name on anything or we don't want the recognition' because they still haven't told people in their life."*

*"I'd like them [newsletters] to be in every doctor's office. I'd like that, but because of COVID we couldn't do that because they couldn't be left on the table."*

**Project-specific challenges:**

**Hamilton:**

- Initial difficulties with organizing ideas for the newsletters; and,
- COVID restrictions limited the distribution of newsletters.

**Haldimand:**

- Team facilitator role precluded input; and,
- Finding an appropriate location for the community mural.

*“The difficult part for me was still being a part of the team, but I had to keep remembering that I was a facilitator. And I had to keep some of my ideas to myself.”*

**Key lessons team members learned:** Lived experience leadership team members identified a number of key lessons in implementing their projects:

- A dedicated Project Coordinator is key to project completion;
- Team members need to work well together;
- Ensure recruitment of team members able to participate and that are a good ‘fit’;
- The local community needs to be open to new perspectives and change; and,
- Project learnings should be shared with others to inform similar projects.

*“[Project Coordinator] was really good at making sure if we needed something it was there, if we had questions and we couldn’t get the answers, [Project Coordinator] really helped out.”*

*“They [Project Coordinator and team facilitator] support us and really encourage you to take your own ideas and really keep reinforcing that its us, that we’re doing it but we have [Project Coordinator] and [team Lead] to rely on. I mean we couldn’t do it without them.”*

*“The four of us really worked together and again, I don’t know if you can plan that.... you also have to have people who have made up their mind they’re going to get along together and work together.”*

*“I think the other thing is to have a community that is open to receiving something that seems to be relatively innocuous in a way, but which does affect the lives of people.”*

**Team Access to Needed Information, Resources, and Supports:** Generally, team members noted that they didn’t have any unmet needs for information, resources or supports and that they were able to secure what they needed independently or with the assistance of the Project Coordinator, who ensured that they had what they needed to complete their projects.

*“I would like to see it continue because we put so much effort into it, a lot of time anyway.”*

*“I think it will [continue] because they’re such a driven team and they’re not going to just give up.”*

**Sustainability:** There is interest among team members to sustain the leadership teams beyond the formal funding period for this project to continue their awareness raising work. There was interest in continuing to promote the Faces of Dementia campaign, conducting presentations to various community groups, producing the newsletter, hosting an annual MICE

festival and developing new projects to raise awareness about dementia.

**Evaluation Objective III: Describe the team projects**

**Dementia Friends in Our Community Quarterly Newsletter:** The Hamilton-based leadership team, has created and disseminated a quarterly newsletter, focused on *Living Well with Alzheimer’s and Other Dementias*, with all content being created by persons living with dementia. Their intention was to use their insights on living with dementia to help others better understand their experience to create more educated, supportive and inclusive communities. The



newsletters contain personal stories, including stories from the care partner perspective, self-care tips, education and brain activities. The team created four newsletters. In total 2,000 printed copies of each newsletter were available and distributed to project partners, local community agencies, leadership team members to distribute to family, friends, and their community and local senior centres; two pharmacies distributed the newsletters through their prescription bags. The newsletters are also available on-line on the Empowering Dementia Friendly Communities Hamilton Haldimand website: <https://coahamilton.ca/our-priorities/empowering-dementia-friendly-communities/dementia-friends-in-our-community-hamilton/>. Access to the online newsletters were promoted by project partners through their programs, networks, and social media accounts (Facebook, Instagram, Twitter).

***Memory Inclusive Communities Everywhere (MICE) Art Contest:*** The MICE team, operating out of the Haldimand region, held an art contest to create a public mural that reflects dementia inclusive communities. Their intention was to share the message that while they have challenges, they are individuals, they are still present, and they are still active and contributing members of their communities with the aim of creating a more understanding, supportive and inclusive community for all persons living with dementia and other cognitive challenges. In March 2022 they launched an art contest to receive submissions from local artists for artwork, with the winning entry being converted to a mural that would hang in a public space. In total, there were 13 submissions. While the intent was to select one winning design, given the high calibre of submissions, an additional two designs were selected. The MICE team partnered with a local pharmacy (Medicine Shoppe, downtown Caledonia) to display the winning entries on an exterior wall of the pharmacy. To celebrate the unveiling of the mural, the MICE team hosted a festival that included words of welcome by two local politicians, public education presentations/speakers, including presentations by members of the MICE team, marketplace exhibitor booths featuring local vendors and organizations, a children’s craft table, and memory Olympics activities.

#### **Evaluation Objective IV: Describe outcomes associated with the lived experience leadership teams and team projects: impacts at participant, partner and staff, and community levels**

##### ***Leadership Team Member Identified Impacts:***

Leadership team members identified a number of personal impacts associated with their involvement in the team:

- Opportunity to be involved in meaningful activities;
- Meaningful use of skills;
- Acquisition of new knowledge and skills;
- Increased understanding about dementia and how dementia affects everyone differently;
- Regained sense of self and self-accomplishment;
- Personal satisfaction with team involvement and projects;
- Satisfaction at having created something that has generated interest and is meaningful;

*“I’ve just been sitting at home. You go from working fulltime to the diagnosis, and then the next thing is I’m not working anymore. ... It [Leadership team] gives me something to look forward to... I like having something to do that’s actually something [meaningful]... I kind of gave up on being any form of contributor to anything.”*

*“Having strengths in my past and being able to draw them out and it’s given me ideas of things that I would like to do to help people with dementia.”*

*“I did learn that things are a lot more achievable than they seem.”*

*“Definitely [learned] a lot about dementia. We’re all so different in our fight with it...”*

*“I have really truly developed some lifetime friendships.”*

- Development of new friendships (finding community);
- Remaining active;
- Reinforcement of the value/importance of being open about dementia; and,
- Increased confidence.

Team members identified impacts that they have observed in their fellow team members and/or other persons living with dementia:

- Increased confidence and engagement;
- Increased engagement in/ contribution in the community;
- Reduced stigma and social isolation;
- Increased social interactions;
- Increased understanding of personal abilities;
- Increased sense of belonging;
- Personal satisfaction with team involvement; and,
- Increased ability to adapt behaviour to allow other team members to be active.

*“They really gained confidence that they can do it. They really did.”*

*“So, it opens their [people living with dementia] mind because when you get a diagnosis, you’re devastated and your mind automatically goes to all the old clichés – you can’t do anything; you can’t leave the house; you’re hidden away; you can’t make any decisions, and I think we’re opening their minds to the point that you can participate, you can stay involved, you can do things. So, I think it is a helpful newsletter in that aspect because they’re starting to see that.”*

Related to community level impacts, it was noted by several team members that community change takes time and thus it might be too early to measure real change; the following observed impacts were identified:

*“I think just opening conversations is usually never a bad thing. So, the fact that it can open conversations in a de-stigmatized way, I think probably has nothing but good things coming from it.”*

*“It seems as if it at least caught some people by surprise in fact that some of us are able to function quite highly in society and even with the disease. And I think that’s something new for people to begin to realize, but there’s a long way to go.”*

*“I think the community got to see a different side of dementia because when people think of dementia their minds automatically go to end stage. They don’t think of that whole period of living before they get to end stage, so maybe it opens their minds to the way they see things, that’s what I think. And I think that everybody is working so hard. I think it’s happening.”*

- Increased conversations about dementia;
- Increased access to the Dementia Friendly Community education workshop;
- Education to others that people with dementia are still able to function;
- Reduced stigma about dementia;
- Improved support for persons living with dementia when in the community;
- Mural is positive addition to the community;
- Increased understanding of disease stages;
- Increased access to information about dementia;
- Encouragement to people with dementia to become involved with the Alzheimer Society;
- Development of interest in other communities to develop similar leadership teams.

**Community-Related Empowerment:** Using the Community-Related Empowerment Scale, leadership team members rated the extent to which they agreed or disagreed with various statements regarding their sense of empowerment as a result of being involved with the leadership teams; results reflected that respondents experienced a high level of empowerment in this project.

**Well-Being:** The Brief Sense of Community Scale was used to measure leadership team members' sense of well-being as a result of being a member of the leadership team; results reflected that respondents experienced a moderate level of well-being within their community. Mean well-being was highest for the group membership subscale, reflecting their high sense of belonging in their community as a result of this project.

**Key Informant Identified Impacts:** Key informants identified impacts associated with the project for themselves as team supports, for team members and community level impacts:

**Personal Level Impacts**

- Increased understanding of the experience of living with dementia;
- Challenged biases and assumptions;
- Learning to support, not lead; and,
- Increased understanding of the resilience of people living with dementia.

*“I’ve learned that it challenged my own personal biases about dementia that I didn’t even know I had... it really transformed the way I even think about dementia.”*

*“I have learned and had the opportunity to understand the resilience, to witness the resilience of people living with dementia and their ability to adapt, to participate in things that are important to them.... I’ve really learned to value, the value of their leadership, the impact that has on the outcomes of a project like this.”*

*“I think what people have said is that this has given almost courage to actually share their story.... They’re now able to be more, I guess, courageous in sharing their story and feel like its actually helping, so they’re speaking with more confidence.”*

*“Well, I think they’ve used various platforms to challenge stigma, everything from news interviews, media interviews, interviews on TV, radio, the MICE Festival did that when they had speakers, the newsletter really offers an alternative narrative to the kind of dominant kind of tragedy narrative that’s so embedded into a lot of materials and where we get our information from. So, I think their activities do that.”*

**Team Members: Personal Level Impacts**

- Increased confidence and empowerment;
- Increased peer support and meaningful friendships;
- Increased sense of purpose with meaningful activity;
- Achievement of project aims; and,
- New skills learned in implementing team projects.

**Community Level Impacts**

- Reduced stigma;
- Development of a new, more comprehensive understanding of dementia;
- Increased resources related to dementia; and,
- Empowerment of people living with dementia.

*“I think it has changed attitudes and I think it will continue to change attitudes and perspectives. I think it will lead to enhanced physical environments and social environments for people.”*

*“What I’ve heard from other people that have kind of seen somebody living with dementia doing this work inspires them to maybe try to do it too.”*

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

- A key theme arising from the project’s community consultation was the importance of empowering people living with dementia through respect, hearing their voices, involving them in the decisions that affect them, and with the provision of appropriate resources to create change. The establishment of the Lived Experience Leadership teams has been proven to be a powerful tool for fulfilling the community’s desire for “*Nothing about us, without us!*” While the projects’ original plan was to procure Requests for Proposals (RFP) from community organizations and agencies to develop and implement community projects, this approach was not consistent with the results of the community consultation, and in fact, worked to disempower people living with dementia by making the RFP respondents the experts in deciding what actions were needed to create dementia friendly communities. By changing the plan to create leadership teams consisting of persons living with dementia, and providing them full agency to make decisions about what they thought was needed to make their community dementia friendly and how they would move this forward, “*Nothing about us, without us!*” was exemplified. This new concept for the Empowering Dementia Friendly Communities, Hamilton Haldimand project is consistent with predominant definitions in the literature that emphasize the importance of dementia friendly initiatives that promote dignity, engagement, autonomy and self-determination of persons living with dementia.<sup>4,5</sup>
- There is increasing evidence in the literature on the prerequisites needed for effectively empowering marginalized groups to affect change in their communities.<sup>6</sup> Many of these prerequisites were implemented in this project to ensure the maximal empowerment of the leadership teams. Moving forward with the creation of the leadership teams required multiple changes to the original plan, beyond forgoing on the plan to procure RFPs. To fully support the autonomy and self-determination of the leadership teams, a change in governance structure was needed to transition the decision-making authority from the previous Steering Committee to the leadership teams, though with support from the Stewardship Group, who provided light governance to oversee the project. The evaluation also highlighted the critical role that access to appropriate resources and supports played in supporting the leadership teams to work together to complete their projects; most notably was the support provided by the Project Manager and Project Coordinator to assist the teams in accessing what they needed for their projects, what individual team members needed to participate fully in the teams, and providing general administrative support (note taking, presentation preparation, fact finding telephone calls, access to information). The use of the CHOICE framework to better understand the

---

<sup>4</sup> Herbert CA, and Scales, K. Dementia friendly initiatives: A state of the science review. *Dementia* 2017;18(5):1858-1895.

<sup>5</sup> Wilkinson H. Empowerment and decision-making for people with dementia: the use of legal interventions in Scotland. *Aging Mental Health* 2001; 5(4):322-328.

<sup>6</sup> Ratna J, and Rifkin SB, Equity, empowerment, and choice. From Theory to Practice in Public Health. *Journal of Health Psychology*, 2007;12(3): 517-530.

leadership teams within the context of an empowerment framework, has highlighted some of the processes and elements that contributed to the success of this initiative, namely, the capacity of building of the leadership teams, the use of a human rights approach in which people living with dementia are actively involved in the decision-making processes, institutional accountability that ensured the availability of needed resources and supports, contributions of all key stakeholders, and development of supportive environments that enabled the work of the leadership teams. This framework has value in planning, implementing, and evaluating dementia friendly community projects and their objectives. In this context, the framework has highlighted the importance of placing persons living with dementia at the forefront of efforts to affect community change, taking into account the interaction of structural, cultural, and environmental factors that can contribute to success. While the project itself, did much to support the empowerment of the leadership teams, the team members themselves contributed to this process by supporting each other's full participation, respecting and valuing their contributions, and fostering a team environment that supported confidence building, self-worth, sense of usefulness and control, all of which have been identified in the literature as important to the empowerment of persons living with dementia.<sup>7</sup>

- Each of the leadership teams were given full autonomy to identify the goals for their team projects. Both of teams identified the need to increase awareness and understanding and de-stigmatizing dementia; while their goals were the same, how they achieved these goals differed, with one team opting to create and distribute widely a newsletter (for persons living with dementia, by persons living with dementia) and the other a community mural depicting dementia inclusive communities. Both of the teams were successful in implementing their projects; one team took their project a step further by celebrating the unveiling of the community mural with a festival that served to further engage the community, provide more opportunities to learn about dementia from those living with it and developing new partnerships for fostering dementia friendly communities. The results of the evaluation confirm that team membership had a profound impact on members, increasing their engagement with their community, providing the opportunity to contribute to something meaningful, reducing their social isolation and increasing their friendships, and regaining their sense of self and self-worth. The use of standardized measures of empowerment and well-being confirmed that these had been impacted by involvement in the teams. Involvement with teams was also a significant experience for those supporting the teams, who reported that their work with the teams increased their understanding of the experience of living with dementia, including their understanding of the resilience and strength of persons living with dementia and challenged their biases and assumptions about the disease to transform their thinking and attitudes about dementia. Although some community level impacts were identified, including impacts on other people living with dementia, as associated with reduced stigma, and increased and more comprehensive understanding of dementia, it was noted that significant community change takes time, and that it is too early in the life cycle of the teams and their projects

---

<sup>7</sup> Van Corven CTM, et al. Empowerment of people living with dementia: An integrative literature review. *International Journal of Nursing Studies* 2021;124:104098.

to measure real change or anticipate impacts that may occur moving forward. The evaluation has highlighted potential community level impacts that can be given consideration as key outcome indicators to explore further in future evaluations of dementia friendly community initiatives. Similarly, key lessons learned in creating the teams and developing and implementing the team projects can serve to inform future projects or the implementation of similar leadership teams in other jurisdictions.

- A key threat to the sustainability of the teams and their projects is the lack of ongoing funding support. As the teams were created as part of a Public Health Agency funding grant, which ends as of March 31, 2023, the future of the teams is unknown at this time. While funding proposals for ongoing dementia friendly community initiatives have been submitted for review, the outcomes are as yet unknown. There is much desire and interest among leadership team members and project partners to continue this work; commitment to this provides some hope that the gains made this project will be sustained in the longer-term.

***Limitations:*** The focus of this evaluation was on the development and implementation of the leadership teams and key learnings from this process. While some attention was paid to the impact of involvement with the leadership team on members, this evaluation did not include an assessment of the impact of the teams and their projects on other people living with dementia or the community, beyond the anecdotal evidence provided by team members and key informants. Future evaluations of dementia friendly community initiatives should strive to evaluate impacts on persons living with dementia and the broader community.