



**Westside
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The Building Capacity Project: Key Learnings about Impacts and Implementation

Below we outline the impacts of the Building Capacity Project as well as learnings about the key elements for supporting community partners to implement programming to achieve significant impacts at the individual and organizational levels, which we will draw on during the project's next phase. We also describe a specific initiative to build knowledge and skill around dementia through the Flipping Stigma toolkit.

What were the aims of the Building Capacity Project?

The overall Building Capacity Project objective was to enable people living with dementia to participate in community life as full social citizens. Towards that end, the project developed and evaluated effective ways to create sustainable opportunities for people living with dementia, and family/friend caregivers, to remain active and connected in their communities through various initiatives as planners and participants. In Thunder Bay, Lakehead University has partnered with the North West Dementia Working Group (NWDWG), an action group of people living with dementia and care partners. In Vancouver, University of British Columbia partnered with the Westside Seniors Hub (WSH), a network of seniors-serving agencies, and more recently the Flipping Stigma Action Group (an action group of people with dementia from across BC). Overall, our hope was to support the growth of a diverse range of innovative community initiatives that foster inclusion and reduce stigma by creating opportunities for people with dementia to remain active and socially connected.

Part One: Impacts -- what did we achieve?

What were the impacts on the individuals involved in the initiative (people with lived experience, care partners, staff, and community members)?

The impacts on people with lived experience were achieved in Thunder Bay through the Dementia Café and Northwest Dementia Working Group (NWDWG), where participants we interviewed described the sense of well-being derived from being able to contribute to advocacy activities that have helped improve the community's capacity for supporting other people experiencing dementia, by influencing policy, educating students, and raising awareness about dementia in the community of Thunder Bay, and in surrounding communities. People with lived experience and care partners have also benefitted directly from the sense of community and support that has come from their participation in the Dementia Café and NWDWG. In both settings, people describe the value of social connections, and how those have benefitted them throughout their involvement, specifically during the pandemic.



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Members of the NWDWG, as well as some of the BC-based advocates (i.e. members of the Flipping Stigma Action Group) have also valued their involvement as educators for the Westside Seniors Hub, helping Hub partners make their settings more inclusive. These partners (community centres, neighbourhood houses, residents' associations, seniors centres, church congregations, libraries, and seniors' day programs) have described the value of learning from the Action Group advocates as well as from their Flipping Stigma toolkit. This has motivated them to learn more about the dementia and its experiential aspects, including stigma, which has helped them become more confident and able to create supportive environments for people with dementia in their own settings. (See below for a description of the Flipping Stigma training initiative).

Together with the seed funding, and direct 1:1 project support, this increased capacity (knowledge, skills and confidence) in turn has facilitated the implementation of new programming (see below) that has increased options for seniors within these organizations that are dealing with dementia, memory challenges, or who are interested in taking steps to maintain healthy brain function. Furthermore, staff, volunteers and program participants from these organizations/community groups have commented on engaging in conversations about dementia outside these spaces, with their neighbours and family members, and into the broader community. The seed funding has also helped Hub partners (e.g. ASK Day program) to supplement existing programming for people with dementia, which has resulted in benefits not only to the well-being of participants themselves but also their care partners, who benefit from having some time for respite.

What are the ongoing organizational impacts of the Building Capacity Project?

The Building Capacity project (BCP), in collaboration with community partners in Vancouver has developed (and in its next phase is endeavoring to sustain) initiatives in the areas of arts, social participation, fitness, and volunteer activities (such as the Happy Memories Café, the Buddy Program, pop up events through the Fireweed Club.) The Westside Seniors Hub, with the support of the BCP's communications team, developed a project-specific website and social media campaign (Soundbytes) aimed at the general public. In Thunder Bay, the project built on previously established initiatives and created deepened opportunities for social participation through the Dementia Café, and opportunities for community advocacy through the Northwest Dementia Working Group. Through the use of the Flipping Stigma toolkit training, in Vancouver, the project has also supported community partners (e.g. libraries, church congregations, existing programs in community or seniors centres, etc.) to become more inclusive of people living with dementia by improving knowledge about dementia, raising awareness of the experience of dementia (including stigma) and increasing dialogue, thereby making community members, staff members and volunteers in these organizations more confident about being able to provide inclusive and effective support.



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What were the impacts on specific subpopulations?

Though we have collected some event-specific subpopulation data in the final phases of the project, we were not able to collect reliable quantitative data on gender and group identity factors that would summarize our project's overall reach for the entire reporting period. However, from qualitative data we can say that our main impacts here include the formation of the Dementia Sisterhood, a virtual support group for women with dementia including members from Thunder Bay, Vancouver, as well as a number of other provinces. Another relevant impact in Vancouver came out of a three-part bilingual training event on dementia organized by the West Point Grey United Church that was conducted in English and Mandarin simultaneously, which increased dementia-related awareness, skills and protective factors in the audience, including some people with dementia and care partners. (Evaluations of this training initiative, which was also conducted with other partners, identified further training needs in the areas of trauma-informed approaches to dementia and intersectional approaches to dementia). Also, as an offshoot of the Happy Memories Café, whose members include a majority of Spanish-speaking members, South Granville Seniors Centre is planning to develop a separate Spanish-speaking Happy Memories Café. Finally, as part of a cross-site event in October 2021, we conducted a series of panels on the influence of culture, language and spirituality on dementia, and shared the learnings of these through SoundBytes, our social media campaign. One key learning was that while stigma may be more prevalent in certain communities, people from racialized communities can find it more difficult to navigate the dementia-care system and access help.

Part Two: Implementation -- how did we achieve these impacts?

Learnings about engaging the community

From our Thunder Bay Partners we learned some key principles for engaging people with lived experience, including:

- the importance of taking time to do the engagement (the Northwest Dementia Working Group evolved over a number of years, drawing on people who were at the point in their dementia journey where they were ready to “give back”
- the importance of having people living well “in the space” as role models (this could help others who wanted to participate but may have been scared or put off by the stigma of dementia)
- the importance of relationships (the relationships are as important as “the work”)

From our Westside Hub Partners in Vancouver we learned about the process of innovation as Dementia Ventures Partners implemented new initiatives. This included:

- drawing on existing resources (which can get around the problem of trying to do something “off the side of the desk”)
- looking for “small wins” (and not getting overwhelmed by trying to do too much)



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- staying flexible (some of our smaller partners were more able to move ahead during the pandemic, drawing on grassroots, neighbourhood relationships)
- using a “ready, fire, aim” approach (not trying to have everything figured out, but moving ahead on something and then reflecting)
- the importance of having a champion at a high level of the organization

We also learned about the value of the Westside Seniors Hub structure itself:

- for “opening doors” to Partner that are ready to move forward on an idea for making the community more inclusive of people living with dementia
- for creating a network for learning together, “being part of something bigger” and making a collective impact.

Learnings about how to support implementation

Through the evaluation, we identified several key elements that are important for facilitating implementation that will form the basis for our implementation strategy in the project’s next phase.

The key elements of the approach, include:

- 1) training about dementia and dementia-related support, including recognizing and addressing stigma (see below)
- 2) engaging/collaboration with people living with dementia
- 3) 1:1 community development coaching, including asset-mapping and plan development, supported by an “implementation seed fund”
- 4) supporting implementation through networking with other initiative partners



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Part Three: Developing the Flipping Stigma Toolkit Training for Dementia Ventures Partners

Background

At the end of Building Capacity Project's (BCP) Phase One, Dementia Ventures partners in Vancouver identified training as an unmet need. For example, as part of the development of its Buddy Program, Kits Neighbourhood House (KNH) volunteers had received Dementia 101 training from the Alzheimer Society of BC (ASBC). This was well received, however partners indicated that they still lacked the confidence to apply their learnings into day-to-day interactions. At the same time, Vancouver Public Library (VPL), which had attended the November 2019 BCP organized event featuring ASBC training, and had expressed interest in some follow up.

As we moved into Phase Two of the project, Building Capacity project staff had also observed that partners were sometimes reluctant or uncertain about raising the topic of dementia, preferring to avoid the topic, or talk more generally about seniors issues. The topic of dementia seemed to be the 'elephant in the room'. As a result of that we considered ways of facilitating more open dialogue. This was an issue that partners themselves wanted help with, along with the general topic of how to engage people with lived experience. With these needs in mind, we facilitated a Dementia Ventures Partner Roundtable in May 2022, which featured the Flipping Stigma Toolkit, Action Group (A.G.) members who had developed the toolkit, and the Northwest Dementia Working Group from Thunder Bay.

At this event, Action Group members talked in concrete terms about the toolkit as a valuable resource for opening up a conversation about dementia; in particular, Partner Roundtable participants heard A.G. members Lester and Cindy Gierach describe how they used the toolkit to stimulate a dialogue with a group from their church congregation. They also heard about the positive impact this had created for Lester and Cindy themselves, as well as for the congregation. This demonstrated the feasibility of doing something other community groups who'd encountered the toolkit had suggested: using the toolkit as part of a training curriculum.

Development of the Training Curriculum and Process

Over a series of meetings with VPL, Dementia Ventures Working Group members and BCP research staff together with ASBC staff developed the idea of integrating the ASBC Dementia curriculum with Flipping Stigma toolkit material to create an educational resource that included both biomedical and experiential material. As a BCP staff member pointed out during the meeting, while "101-type" training can increase knowledge, it doesn't always change stigmatizing attitudes about dementia. Thus, the joint curriculum would address basic information about dementia (signs of the condition, strategies for



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making interactions and environments more “dementia friendly”) as well as experiential content that demonstrated what dementia was like (including dementia-related stigma) from a first-person perspective. It was also aimed at helping trainees discuss the implications for themselves and their organizations, and strategize about how to put their knowledge into practice.

While planning for an event with VPL staff in the winter of 2022, earlier that fall we had the opportunity to pilot the approach with KNH staff, and with ASK Friendship Society. As part of the training, toolkit clips were shown (e.g. A.G. member Donna Wager talking about being told she “*doesn’t look like she has dementia*”, and Myrna Norman having her difficulties at an exercise class being sarcastically joked about by a man who asked: “*what’s the matter – have you got dementia?*”); the session also gave participants the opportunity to share any personal or professional experiences with dementia, and discuss the implications of the vignettes for making their own organizations more inclusive, using a series of guided discussion questions.

Delivery of the Training to Westside Seniors Hub Partners

Two versions of the training were conducted; a joint BCP/ASBC training which was piloted with VPL as one session, and also conducted as a series with the West Point Grey United Church; and a solo Flipping Stigma training, which was conducted for ASK Friendship Society’s day program staff, and for Kits Neighbourhood House staff (and also made available online to all KNH volunteers). Ania Landy, who was originally the Project Manager of the CIHR Flipping Stigma action research project was contracted to coordinate the trainings.

Lynn Jackson, a long-time dementia advocate from the Action Group participated in all of the sessions; the toolkit video of Lynn’s story was played during the session, which stimulated questions from the audience that she addressed during the question and answer segment, along with other audience questions about the dementia journey. Below she describes her perspective on the value of the training:

... the hope is that (staff or volunteers at these organizations) will better understand ... that they ... are people that had a life before their diagnosis and they're trying to continue on the best they can after the diagnosis and might require a bit of assistance at times ...and ... they can be able to know a little bit more what some of the symptoms are or how those people are feeling and be able to look after their needs ... after seeing our presentation.

Impact of the Training

Our evaluation survey asked about the impact of the training in relation to increased dementia-related knowledge, as well as the applicability of the information, from a personal perspective (with respect to the ability to be more supportive), and from an organizational perspective (with respect to facilitating more inclusiveness and belonging in a specific



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agency or organizational setting). We also captured impacts from a qualitative perspective, through open-ended survey responses, and through interviews with key informants (organizational leaders, and our trainer with lived experience).

Summary of Impacts: Quantitative Results

Overall, both qualitative responses and quantitative survey responses showed these trainings were highly valued. In total, 42 participants filled out an evaluation survey. Of those, 88% (n = 37) improved their knowledge about dementia, 90% (n=38) improved their skills or confidence in their ability to use new knowledge, and 95% (n=40) indicated that they anticipated that the training would help them improve the inclusiveness or sense of belonging for people with dementia.

Qualitative Findings

Increased Knowledge

Participants in our trainings (based on the Flipping Stigma Toolkit and Alzheimer Society Dementia 101) valued the complementary perspectives that came from learning about dementia from both a biomedical and experiential lens. They also indicated that learning about brain health in the context of the normal cognitive changes of aging was a good way to transition into a discussion about dementia. For example one senior commented that *“it was useful to learn things I can do to stay healthy and reduce the chance of getting dementia”*

It was also evident that having a person with dementia as part of the training team who also talked about the importance of brain health for her, enabled participants to understand that the same things that helped promote brain health (exercise, social participation, etc.) would also help someone with dementia live a healthy life despite having the diagnosis.

Increased Skills or Confidence in applying new knowledge

Training participants also gained confidence in their ability to put their knowledge into practice, for example by holding further conversations about dementia, using a principle suggested by Lynn Jackson, who emphasized to participants that people with dementia appreciate being asked questions that are well-motivated and coming from a place of *“compassionate curiosity”*. A Vancouver partner talked about how it was important to create a safe space for conversations on difficult topics:

... the education component is so important to everything in life ... just to provide the correct information ... and secondly ... just creating an opportunity a safe place to talk is so important ... [for any] topic that might be something that you wouldn't talk about everyday over coffee for example and ... just providing that supportive environment ...



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and opening that door to begin... to talk about things that maybe feel uncomfortable to some people.

Furthermore, a church partner had the opportunity to discuss dementia in the context of their unique culturally diverse congregation:

Not only are we dealing with two different languages in our church, but we're dealing with two different cultures, so we want to use this wonderful opportunity to talk about dementia as another way to explore and share these cultural differences.

Putting Knowledge into Action

Some of our training participants talked about how gaining knowledge about dementia is important, but they weren't confident they would be able to apply the knowledge without having more opportunity to discuss how the knowledge was relevant to specific scenarios or cases.

With more opportunity to reflect, the hope is that this initial knowledge will indeed spur more conversations, which will lead to the knowledge being applied into concrete action. As one key informant said:

they're all learning and I'm also noticing ... it makes them think about what they can do themselves and how they can get more education ... (I'm hearing people say they've) had a conversation with (their) mom about it or with (their) neighbor about this which also creates more awareness in the community ... I think that's the biggest impact here.

Summing up the experience of others, one Dementia Ventures partner referred to the training, including the involvement of a person with lived experience as a member of the training team, as a "real eye opener." This person talked about how the experience will help remind day program staff that "people had a story before they came here," a reminder that will help staff engage with participants in the future.

The sessions also generated numerous ideas for fostering inclusiveness. At VPL, one learning (based on Donna's vignette) was that dementia can be an invisible disability. This fostered a discussion about developing and posting a visible symbol indicating the organization is dementia-friendly, thus making it safer for people to disclose whether they need support. A VPL leader also expressed an interest in learning more from people with dementia themselves about how they experienced the library. Discussions about stigma being easier to address for younger people generated an idea, at the KNH, for an intergenerational story-telling session hosted during a children's program. This event was



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hosted in the last week of March 2023, with Vancouver's Poet Laurette Fiona Tinwei Lam, on her book *Rainbow Rocket* (about a boy and his grandma's journey with lived experience of dementia).