Building Capacity Project
Developmental Evaluation Phase One
Cross-Site Report
December 2021

Table of Contents

Executive Summary

The story of the Building Capacity project during its first phase (between September 2019 and spring 2021) is about how, coming from different starting points, the two sites developed a shared sense of purpose. Guided by a flexible developmental evaluation approach, it is also the story of how we drew on technology and relationships to adapt to the pandemic, in order to begin moving towards the project's objectives, i.e. to develop interventions that engaged people living with dementia in the community. Each starting point represented a different aspect of community capacity, and a different, though complementary "piece of the puzzle". In each case, the site was able to draw on their respective assets to move forward or maintain previous gains, despite the pandemic.

In Thunder Bay, we began with a solid base of community capacity in the sense of having strong involvement of people with lived experience of dementia, through the North West Dementia Working Group, a long-standing group, which is increasingly recognized across Canada for its leadership. In this site, the challenge was for the project team to move outwards and expand its influence more broadly in the community, while also sustaining the health of the group during the pandemic. The project team initially employed technology to maintain programming and connections. As the pandemic wore on and Zoom fatigue set in, we drew on the group's previous relationships ("chemistry") in order to connect informally and stay together. As the waves of the pandemic ebb and flow, we are planning how to move outwards into the community, focusing on advocacy and expanding the reach of the people with dementia living in the community but not connected to the group.

In Vancouver, we began with strong community capacity in the sense of having, through the Westside Seniors Hub structure, a wide set of partnerships with seniors-focused agencies, mediated by a council of volunteers who enabled us to open doors in the wider community. Through support from the project and the "Dementia Ventures" Working Group, we were able to engage several community partners to nimbly move specific ideas into action using the project's seed funding, despite the pandemic.

In addition, a big strength of the Vancouver site was the mutual interest and complementary assets of the main partners (University of British Columbia and Westside Seniors Hub) in relation to building community capacity in relation to dementia. One challenge was to establish effective working relationships and lines of communication between community and academic partners with relatively little shared history and different ways of working. Certain key events (e.g. the Project Launch Event) were seen as templates for ways of working going forward. Another challenge was to help groups adapt their ideas to the COVID context using technology, while also developing an

intentional approach to engaging people living with dementia. As partners moved into active implementation, they increasingly realized the value of engaging people living with dementia, as well as developed confidence in how to do this meaningfully. The cross-site project Launch Event enabled Westside Seniors Hub partners to learn from the North West Dementia Working Group, as well as from other local leaders we drew into the project who provided positive examples of people "living well" despite having dementia, and were able to share practical strategies for how to engage similar people in their own communities. The Westside Seniors Hub's networking structure facilitated other opportunities for shared learning through online discussions about various aspects of the implementation process of moving ideas into action. Through the asset mapping process and by "leading from behind", the project staff were able to establish individualized relationships and provide support tailored to the degree of partner's assets and readiness to move forward.

Overall, across sites, the project is moving forward by establishing a shared purpose, building a cohesive group, and guided by ABCD and developmental evaluation, is developing processes to build community capacity and meaningfully engage people living with dementia into the community through implementing programming, creating inclusive spaces, and undertaking advocacy initiatives and community events.

Introduction

The Building Capacity Project aims to reduce stigma and promote social inclusion of people living with dementia, in two distinct geographical and social contexts (Westside Vancouver and Thunder Bay ON). This report summarizes the findings of the first phase of our developmental evaluation of the Building Capacity Project (fall 2010 to Spring 2021), describing site-specific and cross-site themes, focusing on the processes and relationships that have underpinned implementation and shaped the project in its early stages in these communities with different starting points and unique assets. As a developmental evaluation, the findings intend to guide continued implementation, identifying strengths to build on, as well as challenges that may require course corrections.

Methodology

As part of our developmental evaluation, we interviewed five key informants and conducted four focus groups, and transcribed the data for coding, using thematic analysis (Braun & Clarke, 2013), using memos to ensure transparency, and employing a team-based approach as well as member checking to ensure the trustworthiness and credibility of our findings (Lincoln and Guba, 1985). Our steps included:

- familiarizing, where all team members read through the transcripts taking initial notes;

- coding, i.e., looking through the data in more depth and taking note of repeating and/or significant aspects of the data;

- identifying themes, i.e. aggregating initial codes into larger categories, using a top-down approach;

- reviewing, naming and fleshing out themes with specific quotes, with site-based sub-teams leading this process, and

- identifying thematic through-lines running through the individual themes both within and cross-sites.

Following our chosen top-down coding framework, the analysis identified sub-themes within the categories of purpose, people (focusing on relationships) and process. In order to member check, we held separate sessions in each of the sites, as well as one cross-site focus group where we reviewed and modified the emerging analysis. For each site, we also incorporated other material (e.g. meeting notes) in order to write a descriptive site backstory to provide context to our analysis.

Findings

Project Backstory

Early in 2018, as the Westside Seniors Hub (WSH) was wrapping up an initiative on pedestrian safety and developing an interest in Dementia, a WSH volunteer Lynn Shepherd invited Dr. Alison Phinney to a meeting so that the WSH could learn more about her community-based research in the area. Dr. Alison Phinney is the co-director of the Centre for Research on Personhood in Dementia (CRPD), University of British Columbia (UBC). Shortly after, in April of that year, WSH invited a presentation from United Kingdom researcher Dr. Gemma Jones who was in Vancouver doing workshops on the Alzheimer's Café. Interest in the model grew, and towards the end of May, a small group of WSH volunteers reconnected with Alison Phinney and her colleague Dr. Gloria Purveen, to discuss their interest in moving forward with setting up a Café. At this point Dr. Phinney offered to link the WSH with a group in Seattle, which had implemented a variety of programs in addition to a Dementia Café as part of their Momentia initiative. The WSH then became more interested in developing a wider range of activities that might appeal to a range of the WSH partners.

At the beginning of the school year, both Dr. Phinney and representatives from Momentia presented at the September WSH Partner's Quarterly Meeting, where the WSH partner organizations and the UBC researchers agreed to continue discussions about moving forward to seek funding for a joint initiative with a broad focus on building community capacity in the area of dementia. In October, WSH hosted a meeting they called First Steps Together, where they developed principles for an initiative, agreeing they would not decide on a specific project but would start with conversations with people with dementia and caregivers.

Fortuitously, over the following weeks, the Public Health Agency of Canada (PHAC) invited Phinney to apply for funding for the Dementia Community Initiative, at that point conceived as a five year, multi-site initiative under the new National Dementia Strategy. Then, in the first week of November, at a follow-up to the First Steps Together meeting, WSH accepted Dr. Phinney's invitation to collaborate on a submission based on the Asset Based Community Development approach. During this period, there were also discussions about other potential partners, including with a group on the Sunshine Coast (a rural area an hour and a half from Vancouver) with whom Phinney had helped the WSH connect. Under a tight timeline, the application was submitted in middle of that month as a two-site project involving UBC and the WSH along with Elaine Wiersma (a colleague of Dr. Phinney from Lakehead University in Thunder Bay) and the North West Dementia Working Group (NWDWG). Dr. Wiersma had led a previous research study called the "Self-Management and Dementia Project" in partnership with the CRPD, and given the natural alignments in their research, Phinney and Wiersma had for some time been looking for ways to collaborate. This opportunity through the Public Health Agency seemed the perfect opportunity.

Early in the New Year as the UBC and WSH partners waited for the funding decision, at a WSH Council meeting Phinney conveyed her expectation that the project would start in February. She also discussed the proposal in more detail, including an engagement strategy that included regular "community conversations". At that point, the Partners identified the issue of need for a strategy or template to engage people live with lived experience of dementia. After UBC learned of the project's acceptance, despite initial hopes for the project to start early in the fiscal year, there were several communications needed between the university and the funder to put the funding in place. PHAC and UBC finally signed the Contribution Agreement in mid-July. Over the next six weeks, staff were hired, and the work began in September, when the first meeting convened of the Dementia Ventures (DV) Working Group, which included WSH volunteers, as well as the UBC personnel (Vancouver Site Coordinator, Project Manager and PI). Over the initial months, the DV Working Group hosted a training event for WSH Partners, and planned for the February Cross-Site Launch Event.

From the beginning, the academic and community partners in Vancouver realized this was a "*dream project*", where each could make unique contributions towards an initiative whose purpose aligned with their respective mandates, where both partners were interested in "*using expertise to build community capacity*," and where each had specific and complementary assets. For its part, WSH could provide an entry point into the community and multiple potential partnerships with seniors-serving agencies interested in building community capacity for people living with dementia. For its part, UBC could bring its dementia-specific research expertise to guide implementation in this action research project that sought to meaningfully engage people living with dementia in the community. As one community leader summed it up: *it's absolutely a dream project because … this is what the Hub was actually … designed for, meaning partnership with … another organization that has an idea or will partner with us on an idea but has our back, has funding…and I think it's also a dream project because we've got the academic [side] and as well as [the relationships] down in the community."*

Overall, the PHAC's conception was solidly grounded in this the convergence between the Vancouver partners (community and academic), and the previous relationship between Vancouver and Thunder Bay lead investigators, which all stakeholders saw as an ideal opportunity to further their mutual interests.

Purpose

When implementing a new initiative, an important consideration is whether there is a clear, shared understanding of an initiative's purpose and how to accomplish it. Below we discuss how a shared understanding of the Building Capacity project evolved across and within each site. We start with Thunder Bay, where this is entwined with the origins and development of the North West Dementia Working Group, a partnership between researchers, people with lived experience, and care partners.

Thunder Bay

The purpose of the North West Dementia Working Group (NWDWG) has evolved over time, going through various "*ebbs and flows*," as the group moved towards a shared commitment to its current mission. This backstory is important for understanding how this shared sense of purpose came about for the NWDWG, both in and of itself and in relation to the Building Capacity Project (BCP). The NWDWG consists of community members Bill, Lois, Susan, Bill, Clara, Ed, Carol, David, Maurice, Jackie, and others, along with facilitators from CERAH including Elaine, Nisha, Ruth, Carlina, and students.

The NWDWG was formed early in 2014. Some members — both people living with dementia and care partners — had been involved as the advisory group for the Self Management and Dementia project led by Elaine Wiersma, funded by the Canadian Institutes of Health Research (CIHR), and hosted at the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University. Once the project was winding down and did not need regular meetings, the group expressed their interest in pursuing other opportunities to work together. Their motivation came out of an appreciation that the project had made their journey easier, and a sense that "*the work's not done,*" since they wanted to make things better for others who were still out there making that difficult journey.

One member, a person with dementia, talking about his previous advocacy work in the community, said: *if I could possibly put something back into the organizations that were helping me, I wanted to try and do that,*" and explained that his motivation to be part of the NWDWG was the same. A care partner, who along with his wife became connected to the NWDWG through the Dementia Café, said: "*we want to keep letting people know, because when [my wife's] three sisters and her mother all had [dementia], they didn't have all these things and there's still some people out there that don't realize what's going on and … we're here to get the word out.*"

With some discussion, as well as exploration of groups in other places such as the Scottish Dementia Working Group, the individuals decided the region needed an advocacy group. They decided that this group would be both for people living with dementia and care partners, recognizing the need to have both groups present to advocate for changes in dementia. With the support of CERAH both for administrative and facilitation purposes, the group continued meeting monthly at the university, which some members noted as significant because it provided "*neutral ground,*" apart from the health system, the Alzheimer Society, etc. As a CERAH staff member explained, *"When you come there, everybody wears one hat and you've just got a common goal that we're all trying to achieve."*

Throughout 2014, the group began to focus on their mission, vision, and values, as well as membership of the group. By the end of 2014, they completed this; the NWDWG articulated its mission "to be a voice for people living with dementia." Its vision is "to ensure that people living with dementia are treated with respect, dignity, and afforded

their human rights," through challenging stigma, raising awareness, as well as advocating for meaningful inclusion and seeking to influence policies and services.

As the Thunder Bay research lead noted, there were times when the group's focus was not clear. She stated, *"There were a lot of times when I just kind of went… I don't know what this is about"* but said there were *"pivotal points of change along the way where it was affirmation again for us that, you know, we're making a difference and we're doing the right thing."* There have been a number of significant accomplishments over the years. In 2015, the NWDWG met with the Deputy Minister tasked with developing the provincial strategy for dementia in Ontario, and shared their experiences and thoughts about priorities that should be addressed in the strategy. In 2015 and 2016, the group worked on developing a standard presentation about what they wanted people to know about dementia, and focused on three key things — stigma, the use of language, and communication. They began to present this work at various forums, including to health care providers, students, and the general public.

In addition, the NWDWG were invited to provide feedback to the provincial government on their drafts of the Ontario Dementia Strategy. Throughout 2016 and 2017, they also began to reach out to local health policy staff to raise awareness about dementia in northwestern Ontario as local health organizations began their dementia capacity planning initiatives. In 2018, the group developed and submitted a successful grant to the Government of Canada's New Horizons for Seniors program to host a conference for people living with dementia and care partners in northwestern Ontario.

Throughout late 2018 and early 2019, the group began to actively plan for this event, and successfully hosted their conference called "Creating Dialogues of Hope: Living Well with Dementia". On September 22nd, approximately 100 people attended the conference from across northwestern Ontario and beyond, which included two Building Capacity (BC) project members from Vancouver. The following day, the BCP had its first cross-site team meeting at the CERAH office, and decided to plan a cross-site Launch Event in February of 2020 in Vancouver, which would be attended by members of the NWDWG and Thunder Bay BCP Team.

Early in winter 2020, the group took a trip to Dryden, a community 3 hours west of Thunder Bay, hosting a public forum in the evening and a luncheon for people with dementia and care partners. As the group took its mission and purpose out to this community, to Vancouver, and to other places, they were surprised at "*how well [*they*] were received.*" Through that reception, they gained further affirmation of their strength and impact, and the importance of their purpose.

Throughout all these activities, the NWDWG has ensured that people living with dementia are out front, leading the conversation. As the Thunder Bay research lead said: "*I really feel like everybody around the table here understands the importance of making sure that people with dementia have an avenue to speak and to influence.*" One of the original members explained the importance: "*… in the past anybody with a diagnosis was more or less hidden away. And the fact that people who have got the diagnosis are*

actually out, can be seen, they're participating; I think that's opened the field to a lot of other people." She emphasized the courageousness of speaking: *"That you're willing to stand up and share your stories publicly, you know, and to have a voice regardless of what that might cost you. I mean that is <u>absolutely</u> massive."* A member talked about how having these new voices out front (including those of care partners) fundamentally changes the conversation about dementia. She said, *"we're just explaining to people there's life to be lived, and we're trying to change the systems in the community to help them function for as long as possible…we're just bringing a different message…a really positive message …rather than the gloomy one that's been out there typically."*

At the outset of the BCP, the NWDWG formed a sub-group called the Community Builders Inclusive Group (C-BIG), which was composed solely of people living with dementia. In line with the mandate of the overall group one of their first activities was to identify community partners they planned to involve in efforts to make their space and programming more dementia-inclusive, which they were able to discuss further, when they travelled to Vancouver with the NWDWG and BCP staff in February 2020. As we discuss below, the pandemic disrupted the C-BIG initiative.

Vancouver

The proposal development partners in Vancouver (UBC and WSH) developed an initial mutual understanding of the project's purpose as an initiative to build capacity for people living with dementia using asset-based community development. The WSH Council would engage partners to implement a variety of initiatives, and the UBC team would support the implementation and evaluation process. The partners also shared a commitment to ensuring people with dementia were actively involved in the process in this action research project. As is common with similar projects, despite the shared understanding there were some challenges around prioritization of different aspects of the project.

One challenge in the early phase of the project was balancing the action and research aspects of the initiative. For instance, a leader within one of the WSH Partner agencies, which had long sought to act on the issue of dementia, found the research slow to get going, and subsequently became less directly involved in the project. As this person put it: *"It [has taken] too long to move ahead, especially when the need is urgent: NOW."* The same individual believed that "[the] *structure and staging [of the research] is too laborious… We're used to getting an idea, putting it together, [and] moving on…. [With* the] *delays with funding approval, [we were] waiting in limbo... while the needs are still there, people are still getting older*." A member of the research team however, talked about "*wanting to slow things down and harness certain activities in the context of a research project where there's an [evaluable] intervention."* She suggests that from the research perspective some of the delays were necessary, and related to the need to create the conditions for doing meaningful evaluation necessary to sustain and grow the initiative. Given these discrepancies in priorities, the learning is that community/

academic partnerships need to surface these different values in a timely way and communicate clearly going forward.

Another related tension was between the desire to move ahead and the realization we may need to "slow down" in order to maintain a focus on engaging people with dementia as meaningful participants in the project. While the UBC/WSH partnership placed a clear value on the primacy of their involvement, during its beginning stages neither the Vancouver WSH/UBC Dementia Ventures Working Group nor its Partner agencies who were embarking on implementation had active participation of persons with dementia. As one of the research team members said: "*the one piece that sat absolutely at the very front for me in doing this work was, this had to be about people with lived experience being at the metaphoric table and I tend to feel like that's the piece that we are at risk of losing the most.* " The same individual also emphasized the need to *"take our time to do this work and in part, because we've got people with us who need time and we can't just charge ahead without them."*

A final issue during the first phase has been to clarify expectations about the scope of the project, and about how much it should achieve during its four-year period. While some team members emphasized the scope of need in the community, others wondered whether it was realistic to achieve significant change at the community level. All agreed, however, that an approach that "started small" and expanded its impact through "small wins" was a useful way to envision our potential impact on the broader community. This conceptualization of the project's impact and how it would come about was illustrated in various ways by the project leadership team such as "*a pebble in a pond with its outwardly spreading waves*", and the idea of the project as "*planting seeds*". A research team member, the Vancouver Site Coordinator, stated that it is important to help prospective community partners seeking to move an idea into reality think in terms that are realistic given their resources. "*Somebody might have a great big plan, but [I help them] to ...make it achievable and to start small and help …hone in on their skills and their assets to facilitate the purpose.*"

Related to this question about the envisioned impact of the pilot project was the question of its sustainability beyond the formal end of the initiative, given that "*this project's not going to give them sustaining funds,"* and as a "*tribute to the enormous amount of work volunteers put into these initiatives."* Comments of focus group participants suggest that there are different ways of thinking about sustainability, including making sure any programs put in place don't "fizzle", are "*integrated into* [regular] *programming,*" and could possibly expand more widely throughout the community. Others talked about sustainability in broad terms of helping to "*change the conversation*" about dementia and how to support people with it.

Sticking with the gardening metaphor one respondent talked about how success could be variable. As this person said: *"Each of those partners, the sod, the soil around their community is going to be different from another and where one seed might take somewhere in one area, it may not take in another."*

Despite these varied expectations about sustainability, all agreed that the project leaders need to be proactive about sustainability planning, and that sustainability to some extent will be dependent on being able to demonstrate and share positive results to key decision-makers who are in a position to help maintain and build upon the project's accomplishments. There was also a recognition that this initiative is part of a broader effort of a number of similar projects and that it order to maximize impact, it may make sense to make a collective effort to share learnings.

Summary: Purpose

In Thunder Bay, the NWDWG had developed a clear sense of its purpose since 2014: to make things better for other people living with dementia through community advocacy. The BCP was conceived as a continuation and deepening of this previous work, where the challenge was how to move outwards into the community to expand the scope of its actions. In Vancouver, a broad sense of shared purpose was established more recently during the proposal development phase about the project (2018-2019): as a chance to build capacity in the community through the WSH Partner network. Though the researchers and community members in Vancouver were jointly committed to involving people living with dementia in implementing specific initiatives, their challenge was how to do this meaningfully in the context of initial project delays where there was a sense of urgency to act, and a realization that implementation would take more time than anticipated. In addition to getting on the same page around pace, another challenge in this first phase has been to manage expectations about the project's scope, and how much can be accomplished during the four-year duration of the pilot project, while at the same time being proactive about developing strategies to sustain and grow the initiatives in the longer term.

From a cross-site perspective, the challenge was not to have "two separate projects", but rather to create a shared sense of purpose despite quite different local contexts and starting points. During the February 2020 Launch Event, one of the lead researchers, Elaine Wiersma, articulated the realization that the two sites represent "two pieces of the puzzle". She stated that in Thunder Bay, "we're working from the inside out", starting with an established community coalition of people with lived experience and care partners, to engage with community settings. In Vancouver, by contrast, the WSH engaged community partners, so the challenge was to move "from the outside in," to engage people with lived experience. The project as a whole thus represents an opportunity for mutual learning about how to develop these two community capacity puzzle pieces and put them together.

People and Relationships

While this analysis shows the importance of having shared values and purpose as a foundation for the work, as discussed below, both sites also identified the importance of having strong relationships to support implementation. This includes the internal working relationships between project members and relationships with individuals and agencies in the wider community.

Thunder Bay

Internal Relationships

While the NWDWG members are brought together by a shared purpose, they also enjoy the social aspects of the time they spend together. Relationships are an integral part of the NWDWG, and complementary to the shared purpose of the group. A NWDWG care partner highlights this as a strength of the group: "*we have a good social chemistry, but we also have a purpose of working towards a common goal... So, I think our strength is based in a social environment as well as a central purpose.*" Members point to the importance of having food at the meetings, and how it can deepen the relationships as well as create a sense of safety. A member living with dementia explained, "*It opens things up and makes it very informal and easier to, you know, to come out with what you've got to say.*" The research lead in Thunder Bay added, "*There's something about sharing a meal together that…helps you have relationships in a different way.*"

Camaraderie and many friendships have evolved among NWDWG members. A NWDWG member living with dementia stated, "*I think … the camaraderie and friendship of this group is just amazing. That's another reason I look forward to these meetings.*" One of the NWDWG care partners echoed, "*The camaraderie is great and I think that we are a very harmonious group as well as a fun group.*" An important part of the camaraderie is the humour. A member said, "*We've had a lot of fun, a lot of laughs.*" Jokes run throughout the conversation, such as one NWDWG member, poking fun at the lack of lunch over Zoom meetings said: "*I joined because I heard about the free lunches, but I'm missing them now.*" Laughter encourages bonding, and closeness in a group, and the NWDWG has no shortage of laughs. Another NWDWG member, living with dementia, affirmed: "*We like to laugh a lot.*" As a researcher perfectly summarized, "*It's not just all fun and it's not just all work. It's both of it together and not just being part of the community, but being citizens of the community, being active citizens.*"

Beyond this sense of camaraderie, an environment of trust, mutual respect, and mutual support characterizes the groups' sense of connectedness. The NWDWG members are not only receiving support, but also giving it; for instance, supporting each other through difficult times, such as the loss of a spouse, and transitions into a long-term care home. The research lead in Thunder Bay reflected on how this reciprocity hinges on trust, "*if something happens to anybody...we're … all there to support them or, to do things or, just be there for them...But I know the group talks about that a lot actually about how, we're there for each other and even the – it is implicit but the trust of actually being able to share your experiences of living with dementia. There has to be a trusting environment … for that freedom and that safe space to actually occur.*"

Along with this sense of safety and trust is a feeling of belonging that comes from being with peers sharing similar issues. As a woman living with dementia described her experience of joining the Dementia Café and speaking to a NWDWG member who was working there as a volunteer: "*when I went to the Dementia Café and I was told that the people there, most of them had Alzheimer's that worked there, I felt like I belong – finally*

belong somewhere now…". She talked about how meeting a NWDWG group member helped overcome her fear and gain a sense of belonging, explaining: *"…(N)ow that I've been diagnosed and any time, at the beginning when I felt, what do I do next or how, what's coming up, I knew I had somebody to go to. And [the NWDWG member] was one of the best people they ever sent me to, to talk with first. When he told me his story and he told me how to deal with it, it has worked 100 million for me."* She has since joined the NWDWG, supports others, and is an inspiration to many. She exclaimed, *"The Café and this group is amazing. I just wish you had all been [there] way back then, to teach other people."*

Community Partnerships

Building on this foundation of internally strong relationships, the NWDWG intends to continue moving outwards into the community to develop the external relationships and partnerships necessary to move forward on their mission.

Vancouver

Internal Relationships

Though the Dementia Ventures Working Group had a shared commitment through the P.I. and key volunteers, in the first phase they were *"feeling their way"* with respect to establishing working relationships and lines of communication, and establishing the respective roles of the academic and community partners.

In this regard, the community volunteers talked about seeing their role as a "sounding board", so that project staff could test planned activities to make sure they aligned with the preferences of WSH partners. Initially, there was some uncertainty from the partners around the project staff's vision for its communications/ knowledge translation strategy, in relation to their own emerging communications role that builds on the WSH website and the WSH Council's role as an "information broker" between WSH partners and the broader community. One staff person explained that the nature of this action research project complicated this alignment, where partners' values about priorities can be different, and where implementation of the project's various facets involves *"laying the track just before the train comes into the station."* Given this complexity, there was consensus that project staff needed to be more proactive about signaling when issues (such as Knowledge Translation) were "coming to the front burner." As one person said, *"communicate, communicate, communicate: you have to constantly keep at it."*

Despite these challenges with communication, and aligning activities within this complex implementation context, the group members talked about *"feeling our way"* towards our *"respective roles and responsibilities"* and developing a sense of solidity as a team as they move forward with the work. One example of a shared success was the project's Launch Event. As one person said, the event was an example of how the project staff used the DV Working Group as *"sounding board"* and talked about how this way of working together contributed to the *"immense success"* of the event. As another said: *The launch was a good example of …the way we can communicate well and we did*

communicate well and we can … communicate better in the future," adding that it exemplified "*the two teams doing best what they could do best.*"

Respondents talked about the group's growing cohesion as relating to these shared successes, but also felt that part of this had to do with the group's commitment to be working through inevitable differences. Said one person: *"there's always going to little bumps, but I've really appreciated the openness."* Others talked about how those relationships have been solidified by a sense of shared commitment to the issue, and deepened beyond the formal work done through the events and meetings. One person said: *we're finding ways of communicating with each other…sometimes in less formal [ways]…there's always action items, but underlying all of that, we do have a shared purpose and a connection that does bring us all together and we all work hard together … to really support each other as a group.*" The same person also referred to the groups' "*comradery around heritage and place*", as they have found a shared Maritimes connection. Another staff member appreciated how a volunteer by hosting an outdoor meeting during the summer had "opened up her personal space" to the team.

The respondents talked about being fortunate for having the chance to meet together several times before the pandemic hit, as well as how the Launch Event helped solidify their relationships. This growing solidity has enabled the group to withstand the disruption of the pandemic and continue the work both virtually and in-person. As one person said, "*we were so fortunate that we had a chance to have several in-person meetings before COVID hit. And we've really been able to continue to build on those.*"

Community Partnerships

During the beginning phases of the project, as it solidified as a team, the Dementia Ventures (DV) Working Group also sought to develop partnerships with the wider community, building on the structure of the WSH as a network. The group talked about the structure of the WSH as enabling the project team to open doors, and DV working group members themselves as a "bridge" enabling them to "stand back" while project staff members develop relationships with the Partner agencies. As one person put it: "*I was always glad that our structure was the way it was…we could immediately put you [the UBC team] in your role, into contact with the partners … introduce you to community and then back off and let you people figure out and the partners figure out how they want to work with you.*"

At the same time, the WSH is in the position to play a role as "information broker": sharing implementation learnings between WSH partners, and communicating about the BCP with the wider community, in order to draw community capacity into the project (e.g. volunteers), and develop partnerships with other agencies. A final and related issue regarding partnerships is the desire to "move a level up," that is, to form strategic relationships with potential funders or agencies that can help sustain the project beyond the duration of the PHAC project, and the overall BCP's Vancouver site's relationship. These strategic relationships may involve other community partners, such as the Alzheimer's Society, the health authority and city, as well as other community partners

who might be interested in bringing resources to the project or taking advantage of the learnings to build similar initiatives.

Summary: People & Relationships

Thunder Bay

Thunder Bay's sense of purpose is built on the foundation of strong internal relationships, which have developed over time within the neutral space of CERAH, catalyzed by strong facilitation that has ensured the partners maintain a clear commitment to centering the voices of people with lived experience despite initially wearing different "hats." The group has established a strong sense of safety and belonging for people who experience dementia, using intentional welcoming strategies, and opportunities for mutual support. Also important in this regard is the role of food, as well as the social environment of the Dementia Café, which has helped members to open up and forge deeper relationships.

Vancouver

As a newer partnership, members of the Vancouver's Dementia Ventures Working Group are finding their way with respect to clarifying their respective roles, and solidifying their working relationships, in a complex implementation complex. In this regard, the group emphasized the importance of clear communication, and maintaining a commitment to working through differences in perspective and establishing shared ways of working. Building on the networked structure of the Westside Seniors Hub, the DV Working Group have identified their role as a "sounding board" for planned implementation activities, such as the successful February Launch Event. The connections of the community DV Working Group members with WSH partners have enabled the project team as a whole to "open doors" and established relationships with several partners in the wider community.

Cross-Site

In keeping with the puzzle pieces metaphor, each site exemplifies different strengths in relation to its internal working relationships and broader community partnerships. In the case of Thunder Bay, the history and resources of the group has enabled it to achieve strong internal working relationships, while in Vancouver the group's network structure has enabled it to quickly develop partnerships within the wider community. For Vancouver, the challenge moving forward will be to develop relationships with people with lived experience and partners. In Thunder Bay, the challenge will be to move outwards and develop partnerships in the wider community. The respective sites have realized, however, that strengths of each provide a rich opportunity for mutual learning. As a cross-site initiative, the project will seek to build on these over the second phase of implementation.

Process

Process, as we will define it here, refers to the specific activities of the initiative and the underlying rationale that knits these into a coherent intervention or strategy. Rather than being guided by a logic model with previously specified outcomes and rigidly defined

steps, our approach informed by developmental evaluation (DE); this entails a principles-based approach aimed at helping partners learn as they go along about which outcomes to aim towards, and to build an understanding of the key principles for achieving these, within diverse complex community contexts. Our project is guided by an asset-based community development (ABCD), itself a principles-based approach which entails mapping community strengths ("asset mapping") and supporting partners to mobilize these in the context of a plan for a specific initiative.

In broad terms, the key aspects of the process as set out in the proposal were engaging the community (focusing on people living with dementia as well as through broader "community conversations"), sharing success stories, and providing direct support through project staff, as well as seed funding aimed at helping community partners move their ideas into action. Below we look at how this strategy has unfolded in each of the sites.

Vancouver

On the Vancouver Westside, the Westside Seniors Hub (WSH) Council, has convened 15 of their partner organizations (PO) for the Building Capacity project (BCP), recognizing the need to foster inclusion and reduce stigma by creating meaningful opportunities for people with dementia to remain active and socially connected. As of fall 2021, six Partners are moving specific ideas into action. In this section, we discuss the ways that the Building Capacity project (BCP) engaged partners and supported them to move towards their goals across Vancouver's Westside neighbourhoods. The main strands of the support strategy include using the WSH structure to engage the community, share success stories through training events, provide resources through an implementation seed fund, and provide ongoing support through networking and individualized consultation within an asset-based community development framework. Below we discuss successes as well as ongoing challenges with respect to each.

Engaging the Community through the WSH Structure

The pre-existing group dynamic between WSH and POs has played a significant role in the success of the BCP to date, through the WSH structure and pre-existing relationships. The WSH serves as a conduit to the community, offering a platform for POs to come together to share ideas and community updates, and the BCP has used this structure as an opportunity to engage the Partner Organizations (PO's) in the initiative. At the same time, the WSH as the nexus of the network has branded PO dementia projects as Dementia Ventures projects and have selected the resilient fireweed as a logo. They have repurposed their website to create a stronger focus on dementia, in the context of a communications plan that positions them as an information broker about project activities, within Partners and the wider community. All of this has helped the project as a whole assume a group identity, which in the end is envisioned as strengthening the team-based approach and commitment to the group amongst Partner agencies about its shared purpose of building capacity for meaningful participation by people living with dementia.

This has benefited engagement, as the PO's themselves value the opportunity to participate in an initiative that enables them to "*be part of something bigger.*"

As mentioned, one ongoing engagement challenge has been to involve people living with dementia more fully into the initiative. Given the concerns of project leaders about ensuring people with dementia are "at the table", in all aspects of moving ideas into implementation, we drew on our network to actively bring people with lived experience in to share their perspectives and strategies. For instance, we included Myrna Norman, a dementia advocate who was the keynote speaker at the launch event, as an active participant in our Community Conversations series. Through the connections with the Flipping Stigma project (an action research project led by the CRPD that involves a team of people with dementia), the team have brought in other dementia advocates to participate in the Community Conversation webinars, and to speak at the WSH Partners Quarterly meetings about opportunities to collaborate going forward. While the WSH has always valued the participation of people with dementia, these activities (including hearing Myrna Norman speak and meeting members of the NWDWG) have been described as a "*game changer*" in terms of "*deepening [their] appreciation*" for the extent of that participation. The question remains, however, of how the project will engage people living with dementia in Vancouver more fully into the project.

Training: Building Awareness about Dementia and Sharing Success Stories

Together with the DV Working Group, the project has hosted a series of training events. The first one in November 2019 aimed at helping Partners understand the basics of dementia and consider how to make their spaces and programs more inclusive. Then in February of 2020, the DV Working Group hosted a cross-site project Launch Event. This aimed at building relationships between research and community stakeholders, and giving Partners a chance to learn about and discuss "success stories", i.e. examples where other communities had moved their ideas successfully into action, including engaging people with lived experience as active participants in all phases of the implementation process. Through this discussion, project staff produced a report that identified a number of for engaging the community and moving ideas into action. One key principle was that any programming should include positive examples of people who are "living well with dementia," (See Appendix A for further detail). Comments from the event evaluation indicated that the value of the event was not only in learning new ideas, but also in drawing inspiration and "confidence" about being able to move forward, in the context of a wider network of relationships of people and partners that could support them.

Networking

Drawing on the WSH's network structure, the project team has hosted a variety of interactive events that serve to bring communities and individuals together to share success stories and experiences of dementia inclusive programs to break down stigma and others barriers. As noted, these events include a 2-day project launch workshop. They also included a 5-part webinar series designed to help Partners adapt their plans in the pandemic context, and ongoing online community conversations sessions focused on

17

supporting the Partners through the various phases of implementation, including engaging people with lived experience, planning, active implementation, and evaluation. While designed to increase knowledge and skills, POs have reported on the value of these events in terms of the *"knowledge sharing, idea sharing, and feeling that you're part of a bigger network"*. The network that the BCP has created is inclusive, and offers a range of diverse perspectives. Fostering connections between organizations and individuals creates opportunities for:

- <u>advice on key topics</u> (e.g. engaging people with lived experience);

- <u>mentorship and modeling</u> (e.g. drawing on the project's cross-site network has helped one WSH partner build on the experience of Thunder Bay's Urban Abbey Dementia Café to implement an online virtual program); and

- <u>collaboration</u> (e.g. networking events enable POs to "*come together as a group... to inform all of the other partners of what they're doing"*; access to a shared network can support POs in identifying opportunities to work together, collaborate and share assets across projects and sites.)

Resources

A key facet of the project's design was to establish an implementation fund, a low barrier process that enabled Partners access to a modest amount of funds to support activities related to engaging the community and cover some costs of new activities. Although modest in terms of dollar amount, these funds were drawn upon in the context of an asset based community development approach. Part of this involved project staff supporting WSH Partner agencies through an asset mapping process to identify existing resources they could mobilize, and to identify promising opportunities to design new programs or make existing ones more inclusive. One challenge the project has faced is engaging Partner agencies who though interested were concerned about taking on new activities "*off the side of the desk*" without any significant new funding they could put "*towards the bottom line*," in a context where sustainable funding for regular program activities is an ongoing struggle. While acknowledging this reality, one key informant however anticipated that "*they'll come forward when they see the support is there.*" As one of our case studies below illustrates, Partners have indeed been able to move forward with modest new funding by drawing on existing resources.

Leading From Behind: Flexible and Nimble Individualized Support

"He stays behind the flock, letting the most nimble go out ahead, whereupon the others follow, not realizing that all along they are being directed from behind." Nelson Mandela.

Another way in which the BCP supports POs is through developing flexible relationships with ongoing communication. At the onset of the project, the community project coordinator scheduled "getting to know you" meetings with POs. The intention of these meetings was to get a clear understanding of the needs, resources, constraints, and communication styles and preferences of each PO. In addition, the project coordinator

laid out the foundational goals of the BCP. This was key to providing customized support rather than a one size fits all approach. Next, with the asset mapping process, project staff have been able to develop a more detailed sense of the individualized strengths and opportunities of various Partner agencies as well as their needs for support. Staff have then been able to support Partners to develop and fund their ideas through the Implementation Fund. As they have moved forward, BCP staff have sought to find ways, as one Partner volunteer put it, to "lead from behind", i.e. to provide tailored support in a way that builds on Partner's readiness to move forward. Through gathering feedback, either formally (e.g. reflection surveys, reflection sessions, or developmental evaluation Partner interviews) or informally (e.g. emails, virtual meetings, telephone calls, or in-person meetings), the project staff are gradually refining their approach for how to best support each PO. As the key informant commented, as the Partners have gained trust that the support is there, they have increased their buy-in to the project.

Partner-Specific Implementation Emerging Themes

Through our evaluation we've also learned about how successes and challenges with the implementation process relate to the practices and characteristics of the Partners themselves, as they've embarked on implementing a variety of initiatives including a dementia café (virtual and in-person), outdoor programming (a bench project), and an initiative to develop innovative adult day program activities. Below we discuss the emerging themes in relation to partner-specific implementation barriers and success factors, drawn from Partner Case Studies, including organizational nimbleness, risk tolerance, timing, and confidence. For the specific case studies, please see Appendix B.

Amidst limited resources and the pandemic, there are a number of factors that helped these groups to move forward. One of these appears to be organizational nimbleness. Compared to organizations such as community centres, which shut down and opened only for "essential work", certain other organizations appeared to have the flexibility to open up more quickly and move forward on new priorities. For instance, the Dunbar Residents' Association, a volunteer-run neighbourhood organization became involved as a partner as the pandemic hit, while city-run community centres were not able to.

This leads to a related factor, which appears to be the degree to which a specific organization is risk tolerant, or whether their structures constrain them to avoid risk. In the case of community centres for example, their social responsibility to minimize risk of transmission made their hesitation to participate understandable and expected. In the context of the pandemic, more grassroots agencies with fewer constraints appeared more likely to step up.

Another organizational factor is timing, or being able to gain support at a time when one can "strike when the iron is hot." In our context, one project, the South Granville Seniors Centre, with a new leader at the helm, inspired by the Building Capacity Launch Event in February 2020, became involved as a partner. Another factor is confidence, which is perhaps less intrinsic to organizational DNA and more conducive to outside influence (e.g. becoming part of a network and learning from similar agencies who are farther

ahead). Potential Partners that have been participating "on the sidelines", watching others move ahead, with the right kind of support from the project, may yet gain the confidence to move ahead.

Thunder Bay

In Thunder Bay, the NWDWG has drawn on its network to engage people with lived experience, and has used the resources (infrastructure, administrative support, facilitation and leadership) from the Centre for Education and Research on Aging & Health (CERAH) to expand its influence in the community.

Engaging People with Lived Experience and Care Partners through Networking & Word-of-mouth

Networking and word-of-mouth in the community largely attributed to the growth of the NWDWG membership. Though the original source of NWDWG members was through the Self-Management Project, the main point of contact with potential members now is through the initiative, 'Dementia Café: A Place to Belong,' run as a partnership between a community non-profit and the university. Dementia Café is a social event that occurs three times a month on Sunday afternoons (pre-pandemic) at a local former church. The Dementia Café does not require a confirmed diagnosis of dementia and volunteers are all people living with dementia or care partners. Community members gather to meet with friends, socialize, and listen to music, play games, or participate in crafts. There is no cost to attend.

Several members of the NWDWG heard of the Café from friends or from members of the local Alzheimer's Society. They emphasized the importance of peer support in introducing them to the Dementia Café, which because of the connotations of the title could create a lot of fear. In regards to the Dementia Café, "*…it's very, very important, I think… [that] you have somebody taking you or for the first couple of times just to introduce you to the situation*." A NWDWG member described the Dementia Café: "*it was a really scary feeling going in, but a wonderful feeling going out.*"

Cafe participants are informed of the NWDWG's purpose and activities in the community and invited to join the monthly meetings. A care partner said, "*that's how we got involved and we're glad we did.*" The creator of the Dementia Café described how she thinks this process of membership has contributed to the NWDWG group's dynamic and success:

> "*One of the neat things that I think actually has really, from my perspective anyways, helped the cohesiveness of the group, but also brought more people into the [NWDWG] group, was through Dementia Café. When we started Dementia Café and I know that many of you, even though it's kind of separate from the group, many of you that's how I met you, or some of you, that's how I met you, but I feel like it gave us opportunity to be together in a different kind of a way and develop some of those relationships as well as to meet new people, you know, living with dementia and care partners who may want to be involved.*

… So, there's, you know, it's been a growing effect I think for the group, but also just the opportunity to get together to hear from other people with dementia and really have our ear to the ground I think in terms of those people who come to Dementia Café who are obviously not all involved here [in the NWDWG]."

Administrative support & infrastructure, leadership and facilitation

The NWDWG's activities are supported by the resources of CERAH, which provides administrative support, infrastructure and a place to meet, which as noted above, provides a "neutral space" so individuals from various backgrounds can come together and "wear one hat." The CERAH staff organize meetings, schedule catered lunches (pre-pandemic), send agendas and minutes from the meetings, and offer several connections and resources to the community. A NWDWG member said, *"One of the nice parts about it is we've got the backing of CERAH and the staff to handle some of the heavy lifting that we've become burdened (some for us) as an organization. So, I mean we've got the back-office support which is really nice."* Members of the group can focus on community activities and issues and do not have to worry about the behind-the-scenes work.

The CERAH staff team includes a Director (Thunder Bay research lead), a research coordinator, two students, a knowledge broker, and two co-facilitators who share responsibilities. As a staff member said: "*the fact that the group works together is because there is the facilitation that people can come and have the safe space and such. But I think we need to sort of really thank the leadership as well.*" In addition to the facilitation and leadership, is the assistance brought by the staff members as well as volunteers. "*Our leadership has a lot to making the success of it, and all the volunteers, especially you, younger people that are out there helping us,*" added a NWDWG member living with dementia.

With the evolution of the group over time and the increasing number of activities the group engages in, the administrative support and infrastructure needed has also grown and contributed to the group's efficiency and success. The Thunder Bay research lead talked about the importance of building shared leadership over time: "*So, that infrastructure and support, you know, looking from the very beginning to what we have now, I think has really helped to improve the group because if it was reliant on me, I think we'd be in very big trouble. So, I just, I wanted to make sure that we acknowledge that, because I do feel like that's been a huge success of the group.*"

Expanding Influence: Ideas for future work

Part of the group's process is always considering how to expand its influence through pursuing new initiatives for the benefit of people living with dementia and their care partners in the community. With all members having different backgrounds, perspectives and connections in the community, there is no shortage of options for the group to visit. The group is always thinking about different ways to get their voice heard. As one member suggested, "*I think too another thing that we could do, the art gallery did have that display about seniors. So, why couldn't we have a display in that room about the*

accomplishments of people who have dementia? Their picture and, you know, have an article about them underneath the picture. That's another possibility for expanding what we do, what people with dementia can accomplish." A NWDWG member living with dementia added:

> "*I think also what we've got to start doing is bragging more about what we've done and get more attention so that - whether it be through the City of Thunder Bay or through whatever media we can, of the things that we've done so we can get more people sort of involved in what we're doing... we can't just be a group ourselves. We've got to get sort of more – get out there. Maybe get an article in the Walleye or a regular piece in the Chronicle Journal kind of thing. I think we can get PSAs in there quite easily. [...] So, I think if we can brag about what we've done, I mean it's nice that we do it, but I think that we've got to tell more people so we can spread the good news, if you will.*"

Another project in discussion is the creation of a promotional and informational video, which can be disseminated publicly, highlighting the NWDWG, its members, and their accomplishments. One NWDWG member pointed out, the video is a way to highlight the group's adaptability during the pandemic: "*do you see a piece in that video, the kind of big main video, to include some of what we've managed to do on Zoom, just as an example of, you know, putting our heads together and coming up with solutions to what looked like an insurmountable problem?*"

Further initiatives group members want to pursue include expanding the NWDWG membership to the entire Northwestern region of Ontario and including the more rural communities. A member noted "*Every once in a while, they have, I think it's called NOMA, Northern Ontario Municipalities or maybe when they have their annual meeting, if they have it here in Thunder Bay, we could make a presentation to them*". Another member added that one way to achieve this could be to: "*send a blanket letter out telling about our accomplishments and just let them know what we're doing to all these different mayors as sort of preamble to being asked to a meeting.*"

Summary: Process

Vancouver

In Vancouver, the BCP has engaged community partners through its network structure, which has also enabled it to bring Partner Organizations together for training events, both in-person and virtual, where P.O.'s have built awareness about dementia inclusivity, learned about success stories, and addressed implementation challenges, such as meaningfully engaging people with lived experience. Other key aspects of the implementation process have included providing seed funding and individually tailored support. While the site has drawn on its wider cross-site network to support implementation (for example, discussing meaningful engagement strategies, and virtual adaptations to dementia café programming), the challenge going forward will be to

maintain momentum in the face of the continuing pandemic while building a base of people with lived experience who can guide continued implementation.

Thunder Bay

With its shared sense of purpose, over time the NWDWG has built a strong base of members, gelled as a group, and created an environment of safety that has facilitated the deepened relationships that complement the group's mission. A key contributor to the group's growth has been leadership of key champions, and the infrastructure of CERAH, which has enabled that leadership to be shared over time. Collectively, the group has used its network (created through the self-management project and the dementia café), to bring in new NWDWG members. Supported by the leadership, facilitation and infrastructure of CERAH, including funding from the BCP, the NWDWG has sought to move further outwards into the community. The group's hopes to expand its influence throughout Thunder Bay and beyond have been significantly hindered by the pandemic, (see page 22 and below).

Cross-Site

An emerging cross-site theme is the significance of networking for implementing this initiative to build community capacity for people living with dementia. In both sites, networking has been key to engaging the community, albeit in different ways. For Vancouver, the networked structure of the WSH has facilitated the engagement of Partner Organizations. In Thunder Bay, the broader network created by CERAH has enabled the participation of people living dementia and care partners who have reached a point in their journey where they wished to give back. The NWDWG provides this opportunity by creating a safe space where people with dementia can be out front leading a different conversation. The challenge remains of how the NWDWG can extend a network in the broader community through which it can expand its influence. For the DV Working group the challenge will be to connect and build a safe base for the participation of with people living with dementia. Both communities have been able to draw on their wider networks to gain access to success stories that have helped them build confidence throughout the implementation process. The February Launch event helped both sites envision new possibilities as they heard about projects elsewhere in North America. Through that event and through ongoing community conversations, the two sites have engaged in mutual learning with respect to their complementary challenges of building a broader base of people with lived experience, and expanding influence in the broader community.

Another cross-site theme is the importance of resources. In Vancouver, this has come from the BCP itself -- which has provided project staff and implementation seed funding -- as well as the in-kind resources of the WSH's organizational and volunteer network. The challenge will be to sustain those resources beyond the period of the project, whether through mobilizing existing assets, or finding new funding. In Thunder Bay, the resources of the BCP, though helpful, play a role in the wider context of the already established infrastructure of CERAH (space, staffing for research, and facilitation of NWDWG's activities) which has been built up over time. The challenge will be to use the existing

resources to connect with and mobilize further resources in the broader community, within the context of the pandemic, which has forced the NWDWG to turn inward and support each other.

Discussion

Responding to the Pandemic

One recurrent issue that ran throughout the implementation themes (purpose, people and process) and influenced all three was the pandemic, and how the two sites were able to adapt. In Vancouver, the project benefitted from having several months of activity before the pandemic struck. As mentioned, key informants talked about having had the chance to establish in-person relationships that they were able to build upon virtually. During this time, the project was able to engage several Partner Organizations, through the November 2019 training event, as well as through their participation in the cross-site Project Launch event three months later where they were inspired by the initiatives of communities that were further ahead. Then, as the pandemic hit, the cross-site project team developed a series of Zoom-based trainings about the possibilities for using technology for virtual program delivery, beginning with a session on virtual dementia cafés, or using outdoor programming to help people "get outside safely."

Thus, when the DV Working Group made the decision to move forward with the Implementation Fund application process in mid-March, five organizations came together, and were able to move forward with implementation. Key informants emphasized the importance of flexibility, with respect to the project team's ability to reframe their activities for the pandemic context, as well as the nimbleness of the Partner Organizations who were able to move ahead, and seize the opportunity to make a difference for seniors whose vulnerability had become more apparent.

In Thunder Bay, the COVID-19 pandemic has significantly affected the work of the Building Capacity project, as well the relationships of the NWDWG. As one member put it, *"the pandemic threw a monkey wrench into all our plans."* As a part of the BCP, C-BIG and NWDWG intended to partner with community organizations, with the intention of creating a more dementia-inclusive community. Instead of moving outwards into the community, however, the group has focused on maintaining the well-being of its members, by drawing on its internal strength as a group.

In March 2020, the group moved to meeting via Zoom when COVID resulted in a province-wide lockdown and the group was not able to meet in-person anymore. This has proved to be challenging and some of the members had difficulty attending these meetings and decided not to attend until everyone is able to meet together face to face. Despite COVID restrictions, some members of the group have informally gotten together outdoors when COVID regulations have permitted this. Additionally, the group planned drive-by birthday celebrations for some members, and facilitators delivered treats for special occasions helped with the social isolation. Throughout the waves of the pandemic,

Group members informally have supported each other, and stepped up when others have experienced difficult circumstances (e.g. hospitalization), such as arranging food, gifts, and other support.

Under COVID restrictions, 2020 also marked a shift in the group when the discrimination against people with dementia and family care partners became significantly clearer to members of the group. The NWDWG identified the denial of visitors in long-term care homes and hospitals, as well as not placing people with dementia and their care partners high on vaccination priority lists as significant issues. In addition, many group members felt that the restrictions, particularly in Ontario, posed significant negative hardships on people with dementia and the physical and cognitive decline was markedly swift in many people with dementia connected with the NWDWG and the Dementia Café.

Thinking back to the original plans, a research team member reflected, "*Perhaps without COVID, we would have more of those community partnerships nurtured.*" However, the group has still been able to maintain some activity, albeit with a different more advocacy-oriented focus, around these issues of discrimination. Concerns such as essential care partner policies in health care organizations and community safety have prompted action by the NWDWG through letter writing and advocacy. Another member reflected that unlike some groups who stopped all activities, the NWDWG has been able to keep momentum. As this person said, "*we're very fortunate I think that we've continued and we're, you know, we don't have big gaps to fill. We're just going to hit the road running really, if we're not already running.*" While the pandemic has created great struggle and loss, it has also been a chance for the group to deepen its relationships. As the Thunder Bay research lead shared *"we've been getting together in more friendship oriented rather than a purpose or project-oriented way, and that has been actually really quite beautiful."*

Collaboration Strategies

Another significant through line is the importance of finding strategies for collaboration, while at the same time centering the voices of people living with dementia. One important partnership is with care partners. In Thunder Bay, the NWDWG has been able to recruit care partners who strongly affirmed this principle, and emphasized the importance of making space for their partners with dementia to speak for themselves. Key informants also identified the importance of establishing a trusting environment where people with dementia as well as care partners could feel safe to share experiences and talk about the issues that were of real importance to them. In Vancouver, the DV Working Group explicitly articulated the central involvement of people with dementia as a value, and has expanded its vision for the extent to which this can and should happen. As it moves forward, there is also a desire to include care partners. In both sites, the relationship with the Alzheimer Society is viewed as potentially significant.

Another important relationship has to do with the partnership between academic and various community partners. In Vancouver, an important learning from the first phase of implementation has been about the importance of finding ways of surfacing and bridging

perspectives of academic and community partners through clear, proactive communication, which is made all the more important given the complex implementation context. In Thunder Bay, having neutral meeting space and strong facilitation has enabled partners from various backgrounds (academic, healthcare, community) to speak to their shared commitment while "wearing one hat." Vancouver, as a new partnership is in the process of developing common practices and ways of working.

In both sites, there is a desire to expand the range of partnerships. In Vancouver, the DV working group wants to increase the number and variety of Partners (for instance community centres) in the next phase. There is also a desire to "move a level up" i.e., liaise with decision-makers and potential future funders who could help sustain and expand the initiative beyond PHAC funding. As noted throughout, in Vancouver the other challenge is to expand relationships with people living with dementia. In the next phase, the project will continue to draw on the advice of consultants such as Myrna Norman, and forge a stronger link with the action group of people with dementia from the Flipping Stigma project. In Thunder Bay, the NWDWG hopes to be able to emerge from the pandemic and resume its vision of expanding its influence in the broader community, to make the journey easier for others living with dementia.

Implications/Conclusion

In conclusion, given the reality of the pandemic, a main learning throughout our first phase relates to the impact of COVID on our purpose, people/relationships and process, and the implications for our work for the remainder of the project.

In Thunder Bay, we learned how important community is, and the people and relationships that comprise it. We also learned how vulnerable those are to being taken away, and the impact on people with dementia when that happens, through the pandemic itself or our institutional response to it -- whether public health orders, hospital or long-term care policies, ethics requirements, etc. -- that kept people apart. At the same time, we demonstrated our capacity for resilience, exemplified through the creative ways we stayed connected.

On the Vancouver side, where the impact of COVID on community was perhaps less severe, we're learning the value of patience, of taking the time for the ongoing challenge of engaging people with lived experience of dementia more directly into our efforts, which is the project's central purpose. We also learned that that despite the pandemic our community Partners people are affirming and even expanding their commitment to that purpose. This was exemplified at a recent event where an initiative known as "Beacon* shining light on Dementia", a highly successful 5 part series on Zoom about Dementia, which was seen by the host organization Pacific Spirit United Church as an important first layer for more direct engagement in the future of people with lived experience of dementia. For Vancouver in general, a main priority for the second half of the project will be engaging people with dementia at all levels of the iniative.

At a cross-site level, where mutual learning has been a central part of our joint process, we are learning about the difficulty of doing that work, when we cannot meet together in-person, and the pandemic has disrupted momentum in both sites for doing anything outside of their own sites. The question is how we can restore that impetus and look for opportunities to bring the project's two puzzle pieces together, for example, thinking about how to connect a church group in Thunder Bay with the Beacon Project in Vancouver.

The impact of the pandemic was different in the two communities. However, we realize that the pandemic can be an opportunity, that calls attention to societies' 'most vulnerable' and creates an impetus to think about how to do things better, and how to involve people with dementia in the building back process, realizing in the end that community is what makes life worth living.

References

Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. London, UK: SAGE.

Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, Ca: Sage Publications.

Appendix A: Implementation Principles

The following were identified during the February 2020 Launch Event. They represent emerging principles in relation to interventions to build capacity for meaningful inclusion of people with lived experience of dementia. Principles were identified in relation to program design, program implementation, as well as program sustainability.

Program Design Principles

- Innovative programs and ideas should be driven by people living with dementia

- Creating programming based on stage of illness is less important than asking, "Would person X enjoy the experience within it?"

- Innovative programs should support empowerment and self-advocacy of people with dementia and their care partners

- innovations that are designed based on the principle of "joint respite" have been shown to be promising (i.e. where both the person and their partner can have a chance to have their own outlet)

- educational initiatives that are led by people with dementia and their support partners, where the presentation material draws on their own experiences, can be a powerful approach for raising awareness and addressing stigma

- programming is most successful and rewarding for people living with dementia when it is designed around being present in the moment and when it focuses on the abilities of people living with dementia

- programs and approaches need to be dynamic and fluid to remain inclusive, supportive, and effective, to acknowledge the fact that no two people living with dementia are the same

- innovations must create an environment where people can "see themselves", and see healthy examples of others living well with dementia. (e.g. Paul's Club)

- innovators should strive to create an atmosphere that is welcoming and where people can find a sense of belonging

- successful or promising innovations often start small and first aim to create an inclusive welcoming atmosphere (e.g. by hosting a Dementia Café); further ideas can emerge out of this initial success

Program Implementation Principles

- The health care landscape, or the community at large has policies (e.g. bylaws) that make it difficult for new innovations to find a niche, so innovators must be prepared to experience frustrations and be ready to be entrepreneurial (e.g. Paul's Club's, found a way to get around being classed as a "restaurant")

- Because new programs may not be perceived as fitting within the healthcare landscape, selling one's idea may be difficult at first, so be prepared to cultivate allies over the long term (be prepared to walk away from "closed doors" and look for open ones).

- Finding the right venue, or right partners can be difficult at the outset, so innovators must be prepared to reflect on setbacks and develop a "Take 2" that addresses these challenges (e.g. NWDWG's first attempt at a Dementia Café was a "flop")

- Engaging people living with dementia can be difficult (especially at the outset) so try to base program ideas on their ideas about what would make a worthwhile initiative; by starting small and building on success (and reflecting on setbacks) it should be possible to engage an increasing number of people over time

- There are numerous ideas out there, but when basing one's own programming ideas on other programs it can be challenging to understand the ins and outs of the model, so network closely with innovators, draw on their resources (e.g. toolkits) but be prepared to make adaptations based on your local context

- The need to find new program funding can be addressed by trying to draw on and adapt existing community assets (after making these adaptations, build information about accessibility into existing program listings)

Principles for Sustaining Innovations

- The challenge of maintaining successful funding over time can be overcome by building evaluation in to the effort, and communicating results using both numbers and stories (or other creative approaches)

- Adapting existing programs to be more inclusive of people with dementia can create extra pressure on personnel, so staff must be educated and supported to perform this new role

- Adapted programming is not always accessible or safe for people living with dementia, so programs must also allow space for support partners, and also address cost barriers (e.g. by providing a free pass to support partners to adapted community centre programs; e.g. by providing parallel supports for partners, e.g. Frye Museum)

- The needs of people with dementia can shift over time to the point where certain individuals may no longer be able to take advantage of given offering; a strategy here is to anticipate the need to develop a transitional strategy (e.g. the "Bridge Program offered by the Frye Museum")

Appendix B: Westside Vancouver Phase One Case Studies

Note: these case studies represent the situation at the project mid point.

Partner One: Ready Fire Aim: for this Partner, the Implementation Fund was released at a time of top-level turnover, low resource levels, and a public health order pandemic community shut down. *The funding came through very quickly, compared to our ability to actually take it on because we're such a small centre and we were just struggling to deal with the day to day".* However, the needs of the community still existed, and new needs were quickly emerging. Inspired by the Launch Event and building on the work and commitment of the previous Executive Director to the issue of dementia, and their knowledge of members: *"We just dove in".* They did not know where to start, but they had to do something quickly. Through the facilitation of a DV Working Group volunteer, the PO staff immediately reached out to the project team for guidance. Subsequently, the BCP connected them with an organization in their network who has been running a similar project for years, which invited them to participate in a virtual program session to see what the program looks like in practice. This was followed by an opportunity to ask questions and learn more about how to implement a similar type of program, which provided them with the confidence to apply what they had learned to their own community context.

Responding quickly to the growing needs of the community far outweighed the need to plan things perfectly. As the Executive Director framed it, this group adopted a "ready, fire, aim" approach and quickly mobilized available resources, set a date, and ran their first program. They were able to learn on the fly as they incorporated aspects of program planning and evaluation into program delivery. Asking attendees for feedback during sessions enabled program staff to tailor future sessions based on interest. In addition, between program sessions, the PO connects with the BCP community program coordinator to debrief, where they discuss what went well, and how to overcome some of the challenges, including how to talk safely about dementia, and helping the facilitator build confidence in this new program setting. As with all new programs, an important question is how to engage people and make them feel safe entering a program related to a stigmatized topic. In this regard, the agency has built on previous relationships with participants. As their ED commented, one of their key learnings is that "the conversation is more important" than focusing on dementia itself. Building on the advice of a dementia advocate involved in the project, the BCP project has also shared story-based approaches for discussing dementia, which can be a more hopeful way of fostering dialogue, compared to some academic or medical material about the condition. The PO is well represented at BCP group activities, and shares their experience with others, while at the

same time learning together with the group. All of these steps, allows them to refocus, recalibrates, and aim to create a stronger more sustainable program next time.

Partner Two: Small Gestures, Big Impacts: Another PO is comprised of a passionate group of volunteers who recognize the need, "to come together as a neighbourhood" and support their community. Rather than having a small project team to plan and deliver a project, this PO relies on leveraging the collective assets, skills and talents of an entire neighbourhood to take collective action. Their first step was to raise awareness by opening up discussions with individuals and businesses, in both public and private spaces. According to the leader of this group, COVID had raised a particular concern about isolated and vulnerable seniors within the neighbourhood. At the same time, the pandemic has created "an openness to communicate and share ideas", and the PO reacted swiftly to identify opportunities. Relying entirely on volunteers, the PO recognized the benefit of starting with "a small gesture to say we're all working together". An example to illustrate the "starting small" philosophy is the bench project. This started with the realization that benches are often available outside of churches and in parks, and can be re-envisioned as "dementia-friendly spaces" that can be "made available for those living with dementia as a quiet place to sit and have a little lunch". Building on this insight, the PO invited a summer student to map out the location of all community benches on a map. Starting with a simple easy to implement concept, and by being able to demonstrate the desired impact is an effective way to encourage community buy in. It can create a ripple effect, that "can be expanded on, and we can ask, what next?" **Scaling up, be a model for others to follow***

Partner Three: Getting On with It: a third PO would have liked the BCP to "move faster" as they felt that the needs of the community are outpacing the ability of the BCP to support solutions. The PO is "used to getting an idea, putting it together, and getting on with it". During the lead up to the official project start, this Partner Organization was one of the most ready to participate. However, with the delayed timing of the research project, there was concern about keeping volunteers engaged who may wish to move on to other things. There is also an apparent mismatch between the culture of this PO and the structure of the BCP, which is seen as "laborious." In contrast with other Partners who gained confidence and readiness from the project training events, there was a sense in this PO that these were "redundant". Because the project team was not ready to support this PO when ready, they may have missed an opportunity. However, one small success is that the PO is still indirectly engaged and self-selects to participate in events that are of interest to them. The conversation through the project has also resulted organically in an initiative (the Beacon Project). Though not aligned with BCP this project seeks to increase the inclusiveness of a congregational setting for people living with dementia.

Partner Four: Moving things "off the side of the desk"

This is a partner that has been involved in the BCP but a setting where involvement has been hindered by the pandemic. This Partner has a reputation for engaging the community, assembling resources, and creating solid programs. From an outside

perspective, they appear to be have been less comfortable with moving ahead in a situation with few new resources, and where existing staff are maxed out. Nonetheless, they have started moving ahead with a community consultation process, including developing an advisory community of people with lived experience, to plan a friend program to support people with dementia to participate in their programs. Throughout this process, the BCP Site Coordinator has adopted a strategy of "not forcing them", waiting for them to ready and when they are, "being there for support." An initiative that was "on the side of the desk" has now begun moving into the day-to-day practice of this community organization.

Partner Five: Finding Ways to Stay in Touch

This Partner has used their long experience with providing day programming for people with dementia to move ahead and develop creative programming. As the pandemic has disrupted their routines, their activities have focused on ways of staying in touch with members at home through phone check-ins (for both members and care partners), and by adopting virtual programming features. With the pandemic and the upcoming move to a new space, BCP activities have understandably moved towards the backburner. Nonetheless, this Partner has remained actively involved in BCP events and network.

Acronyms

ABCD   Asset-based community development

BCP   Building Capacity Project

C-BIG   Community Builders Inclusive Group

CERAH   Centre for Education and Research on Aging and Health, Lakehead University

CRPD   Centre for Research on Personhood in Dementia, University of British Columbia

DV   Dementia Ventures

NWDWG   North West Dementia Working Group

PHAC   Public Health Agency of Canada

PO   Partner Organizations of the Westside Seniors Hub

UBC   University of British Columbia

WSH   Westside Seniors Hub