



The Building Capacity Project's Phase Two Networking Event

February 28th, 2024

The Building Capacity Project kicked off phase two of its initiative with a lively online networking event February 28th, 2024. Both new and established community partners introduced themselves to each other, presented their initiatives and hopes for going forward, and had a chance to connect in small breakout-room settings. They explored some of the challenges around engaging people with lived experience, and the elements needed to make places and spaces more inclusive. They also discussed strategies for making programs sustainable long-term and reducing stigma around the word "dementia".

The Building Capacity Project began in 2019 when the research team received funding from PHAC to work together with the Westside Seniors Hub in Vancouver and the North West Dementia Working Group in Thunder Bay. The project's purpose was to build capacity for meaningful engagement of people with lived experience of dementia in their communities. Over the next four years of phase one, we partnered with community groups like Kitsilano Neighbourhood House, The Dunbar Residents' Association, ASK Friendship Society, West Point Grey United Church, and South Granville Seniors Centre to learn about dementia and try out new ideas for how to be more inclusive.

Now, as we begin **phase two**, we've welcomed several new partners to the project including Burnaby Neighbourhood House, Purple Angels, Burnaby Co-Creation Academy, and Sunshine Coast Resource Centre with Gibsons Seniors Society out of Harmony Hall.

Here are some of the plans and priorities our partners discussed:

Kitsilano Neighbourhood House (KNH) is building on the Memory Buddy program it created in phase one, where volunteers pair up with people with lived experience of dementia and spend quality time together twice a week doing mutually agreed upon activities. *"It's been a slow take off. So, getting the right wording on posters and promotional items is very important—getting people to understand it's not just about the participants, it's also about providing a break for the caregivers. And the program isn't a medical thing, it's a social program."*

ASK Friendship Society is expanding and developing their bus rental program, focused on subsidizing costs so the service is more accessible for all. *"We know transportation and cost are barriers for other organizations. So maybe we can find a way to really discount that for them. So, you can pick up your seniors, take them to an event, and then bring them home again,"* said Miranda Haley.



South Granville Seniors Centre continues to run a Happy Memories Café in both English and Spanish, where it hopes to expand capacity in phase two. This is a once-a-month gathering to share memories, enjoy a meal together, engage in some learning, gentle physical activity, and brain stimulating games or challenges. They're also keen to connect with the Flipping Stigma Action Group for guidance on engaging people with lived experience of dementia in program planning and design. And they're grateful for their bilingual volunteer base, who can support both language cohorts.

Dunbar Residents' Association piloted three main projects in phase one, which they're building on for phase two. They took on a bench and walking route mapping project, a collaborative community gardening initiative, and a field trip program, getting community members out on the bus (rented from ASK) to enjoy the city beyond their neighbourhood. For phase two, they hope to explore how they can make their broader community more inclusive, as well as develop some dementia-specific activities. Through these activities they also hope to create a Dementia Action Group to ensure their work is consistently guided and informed by people with lived experience.

Gibsons Seniors Society and Sunshine Coast Resource Centre are new to the project, and eager to make their programming at Harmony Hall more inclusive of people with dementia, as well as develop some dementia-specific programming. They are conscious not only of fear and stigma around dementia, but around aging as well. *"We have to just take one tiny step back and make sure all our communities are welcoming and understanding of aging in general. There tends to be an unspoken bias about older folks whether they've got perfect capacity or not. And I'm honestly quite tired of being referred to as 'dear'."*

Burnaby Co-Creation Academy is also a new BCP community partner committed to supporting people with lived experience of dementia to have more opportunities for participation and belonging in community. Their focus is on involving people in the co-creation process of creating new spaces and opportunities in a way that fosters creativity and joy. *"There is always a creative way to solve a problem or create something new. First, we need to practice how to listen actively, as that's an important sign we are not judgmental."*

Though the group has been going for some time, **the Purple Angels** is new to BCP, and is hoping to build and sustain its activities through this initiative. Leader Myrna Norman expressed how important it is to read the people coming into the support group. *"We really have to understand their likes and dislikes. I've tried crafts on three occasions. And on one occasion, a man and his wife left because he wanted nothing to do with crafts. So that was a lesson I needed to learn."* The collective goal of the Purple Angels is around enjoying life, maintaining a sense of hope, and reducing the stigma around dementia. They have an exciting line up of activities ready for the year ahead as well as some public events to raise awareness.



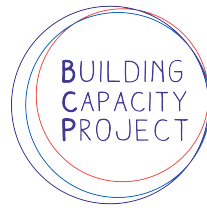
Burnaby Neighbourhood House is providing social and recreational programming for seniors in BC Housing sites, with the hope of making them more inclusive of people with dementia. But they have faced significant stigma and push back in the process. *“A couple of people have actually come up to me and said, ‘Oh, if this is going to be serving people with dementia, we don’t want to be a part of it.’ And that’s been disappointing,”* said Leila Habibi who is involved in coordinating the BC Housing initiative. She also commented on ways of making BNH’s other programming more inclusive to people with dementia but expressed the challenge around language barriers. *“A lot of Farsi speakers are bringing in their parents, so this is a factor when we are training our volunteers who want to offer peer support.”*

Some of the goals and learnings from the event:

One of the biggest challenges partners had in common was engaging people with dementia in their programs and initiatives. Due to the societal stigma around dementia, and the resulting self stigma, community members expressed concern that people might resist attending anything that included **“dementia”** in the title. Some groups who had been at this work for a few years already felt community-wide awareness campaigns and education had significantly helped reduce stigma in their circles and had given those with lived experience an increased sense of safety. Others, for whom dementia programming was newer, eagerly embraced starting the process of helping their circles become more comfortable. By taking a more inclusive approach that framed the topic in terms of memory challenges or brain health, they hoped attendance would increase and they could more readily spread awareness, model capacity, and build connection. The partners had varying degrees of success and a range of experiences with how their respective communities received their efforts, and they found it helpful to hear about these from each other.

“I had great difficulty hosting our Purple Angel Café when it was called “dementia support” because people didn’t want to come,” said Dementia advocate Myrna Norman. *“Now that it’s called a “memory café,” I have no problem.”* She explained further, *“As much as I’d like to say, “let’s use the word dementia all the time” [with respect to inclusive programs and services], the world just isn’t ready. We just need to get people to come out. So, however we frame it initially, is right.”*

Kitsilano Neighbourhood House Seniors and Housing Coordinator, Thais Lopes, described how their initial approach to recruiting people with dementia pivoted and transformed. *“When people were reaching out to us initially, and we explained how things would work as a group, many of them said, ‘oh that’s not for me, I don’t feel comfortable.’ They didn’t know anyone; it would have been a group of strangers to them.”* Kits House quickly shifted to a one-to-one, relational approach. *“We hoped eventually these individuals would build connection to others and develop community organically,”* said Lopes. That’s what happened. The relational approach proved highly successful in their context.



On connection and belonging

We discussed the importance of establishing connection and a sense of belonging in helping people feel safe to attend programs, share, and engage. We explored how making a space inviting, inclusive, and free of judgment would set up a group to connect and bond on their own terms.

Burnaby Co-Creation Academy Co-Founder Farhad Farhang explained what an architect friend told him: *“human beings make the environment and then in return the environment that’s been created builds them. So, space is really important in giving that sense of belonging and connection.”*

Program facilitators can make space for group members to build their own connections to each other by being flexible, actively listening to the priorities of participants, and getting creative in their program offerings.

Myrna Norman gave a great example of this from her Purple Angels group based in Maple Ridge. *“It’s not what we do as facilitators, it’s what [participants] do as a group. They bond with each other, and those bonds become so strong. In one of the groups I facilitate, I have two fellows who are nonverbal. I managed to have them sit together to play X’s and O’s one day, and they couldn’t figure it out. One gentleman had never played before, and the other couldn’t explain it. But they sat together for over an hour, communicating in some way. And that’s what it’s all about. It’s about the people who come into the group bonding to each other.”*

On sustainability:

When we turned the conversation to sustainability and the kinds of things partners can do to ensure their programs endure well after the funding dries up, Project Co-Lead Dr. Elaine Wiersma shared her thoughts.

“The first thing I’d recommend is finding your champions, because they will be the ones with the passion and excitement for the work you’re doing, and they will help carry that on long term.”

“Secondly, don’t just count on your champions. One of the reasons why our Dementia Café is so successful is because we’ve built a group of fantastic volunteers who all understand the philosophy that everyone who walks in the door belongs.”

“Lastly, don’t underestimate the value of what people with dementia bring to the table. They are your volunteers, and they are the ones living this experience who will want to make sure what you’re doing succeeds. Invite them to be part of the change, not just the recipients of it.”



Looking forward:

Community Research Director Andréa Monteiro reflected on our collective goal for the next couple of years, saying, *"By the end of phase two, through the Action Guide, we will have a road map to help other groups with what we learned in phase one, and what we're learning together now over this next year and a half. These learnings and challenges will tell the story of how we walked alongside each other."*

In the short term at the Vancouver project site, now that community partners have had a chance to share their plans and get feedback, the next step will be working individually with our Community Research Coaches to flesh out their plans and think about evaluation. They've connected with and learned from each other, and they will have future opportunities to connect again and even collaborate on certain aspects of their work, including an in-person event being planned for the early fall of 2024.

In Thunder Bay, the team is expanding the scope of their work beyond the city itself. *"For the last four years, we've been focused on Thunder Bay, and our opportunity now is to expand that out to surrounding municipalities and townships,"* said Project Co-Lead Dr. Elaine Wiersma. *"The beauty of working with small communities is that many of the kinds of relationships we've been trying to build in larger centers like Vancouver or Thunder Bay, already exist there,"* she said, referring to established personal ties with members of municipal government and other policy influencers.

As part of the Community Action Team, people with lived experience and community champions from both sites will continue to work together on developing and completing the Action Guide. This tool will share our learnings about all the stages of taking an idea and putting it into action, and we look forward to putting it out into the world as a resource for others looking to develop dementia inclusive communities, so we can continue to scale out our efforts. As Project Co-Lead Dr. Alison Phinney said, ***"this is not 'just another project.' This is about social transformation."*** Making a paradigm shift of this magnitude takes time, space, reflection, and persistence. And the Building Capacity Project Team and its partners are up to the task.

"I don't think we'll ever solve the issue of ageism or stigma around dementia. But visibility goes a long way to address it. The more people can see that I can choose my own apples or operate well in a grocery store... that does have an impact. We will never know the impact. But I know that it has one."

~Jim Mann, Dementia Advocate, Member of the Lived Experience Research Advisory.