

The Building Capacity Project

Inclusive communities for people living with dementia



"What if we replaced the persistent rush to establish "what is the case" and began to ask, "what kind of world could we build?"
– Kenneth Gergen, 2016

The Building Capacity Project identifies concrete ways communities can become more dementia inclusive. The interests and expressed priorities of those living with dementia are at the centre of this work. Together with people living with dementia, community organizations and university researchers guide the design and implementation of new initiatives and capture knowledge about what works when it comes to making communities more dementia inclusive— and why. These learnings will inform future policies and priorities in community and health settings— and provide a roadmap for more dementia inclusive communities.

Who We Are

UBC's Dr. Alison Phinney and Lakehead University's Dr. Elaine Wiersma partner with community leaders in Vancouver and Thunder Bay on the Building Capacity Project. Both sites feature a research team and coordinator paired with a "backbone" community group. The backbone group works closely with other community groups, organizations, and people with lived experience to form an interconnected web of support. In Vancouver, the Westside Seniors Hub serves as the backbone. They're a highly committed group of volunteer professionals connecting people and organizations, spreading word about program offerings. Thunder Bay's backbone is the North West Dementia Working Group. Comprised of passionate volunteers exclusively with lived expertise, the NWDWG is uniquely positioned to listen to, hear, and advocate for people with dementia.

The two teams distribute seed funds and nurture dementia inclusive opportunities in community. They encourage and facilitate new initiatives in their communities. Though each site launches from a different place and context, they both engage people with dementia and community organizations in different ways and act as inspiration for other communities across the country.

Launched in 2019, the Building Capacity Project was the first collaborative initiative of its kind to be set in motion under the Public Health Agency of Canada's Dementia Community Investment Strategy. The initiative runs through to 2023 with the goal of creating a legacy of sustainable impact and positive change for people living with dementia.

Our Process

The Building Capacity Project empowers people and organizations through a unique project approach. People living with dementia are united with community organizations positioned to offer engaging programs. This project helps these organizations make existing offerings more inclusive for those with lived experience, and spurs them to create new initiatives. Programs like these, then, function as stepping stones towards dementia inclusive communities on a broader level. Some of the kinds of organizations involved include: recreation centres, church groups, libraries, seniors' centres and neighbourhood houses. The needs and concerns of people living with dementia are always at the heart of everything, as the goal is equal access for all and opportunities for active and meaningful engagement.

Community Action Highlights

Vancouver

The Westside Seniors Hub facilitates projects through several unique organizations. Examples include:

- a park bench project, which maps out resting places in the community for those with dementia (Dunbar Residents' Association)
- a buddy program, providing social connection and conversation (Kitsilano Neighbourhood House)
- a virtual dementia café offered in 2 languages (South Granville Seniors Centre)
- a collaborative of outdoor walking groups, gardening clubs, and open-air arts workshops (Several teams working together)

Thunder Bay

The North West Dementia Working Group has supported several key initiatives. Examples include:

- Dementia Café: A Place to Belong, originally held at Urban Abbey, that went virtual at the onset of the pandemic
- a "Living Well with Dementia" conference in Thunder Bay featuring both keynotes and panel-style discussions led by people with lived experience
- presentations in Dryden, Ontario to engage those in the region
- an analysis of library reading resources on dementia

Across sites, the project has partnered with a podcast called "Dementia Dialogue" hosted by David Harvey. It's funded the production of one episode so far entitled "Grassroots Change Makers", with plans to support production of three more this fall.

Tracking Our Progress



The Building Capacity Project team facilitates, supports, and observes the community-led dementia inclusive programming in Vancouver and Thunder Bay. Through a developmental evaluation approach, the team is learning how to best support communities to engage people living with dementia, and move their ideas into action. By providing individually tailored support and establishing an implementation network based on its hub structure, the Vancouver team is helping its partners move forward. The Thunder Bay team is showing the benefits of a long-term process that builds from the base of the North West Dementia Working Group, established prior to the formal start of the Building Capacity Project. Together, the two teams are sharing learnings about how to create synergy between lived experience and grassroots community organizations.

Impact of COVID-19

The pandemic meant the closure of many community programs this past year. But galvanized by the vision of more inclusive communities for people with dementia, both the Vancouver and Thunder Bay teams have endeavoured to pursue their goals and plans. They embraced new safety measures for in-person gatherings and climbed steep learning curves to “go virtual” and find ways of getting outside safely. Despite a few time line delays, the project is thriving—an undeniable sign of the persistence, resilience, and tenacity of its communities.

A Case for Community Engagement

Dementia is a growing concern: 76,000 Canadians are diagnosed annually (a number that will increase by 68% over the next twenty years), and they are living with dementia for longer. Our healthcare system is simply not designed to meet the needs of this group.

That’s where a community approach can be a crucial and progressive part of the solution. Building capacity in communities across Canada takes pressure off healthcare services by offering a complementary array of programs that engage people living with dementia at different points along their journey. Program costs are shared across organizations, and grassroots expertise grows to include community professionals and volunteers who provide artistic, civic, social, and physical activities. People living with dementia are part of that pool of expertise, benefiting from bi-directional sharing of teachings and learnings. They gain an enhanced sense of belonging in their community through participation **and** contribution. They have the autonomy to choose—and be part of designing—programs and services that are personally appealing, and that have their social, cultural, and geographical context in mind. Plus, care partners feel bolstered and supported in their own neighbourhoods by people they know and see regularly at the local coffee shop, rec centre or dog park.

Building capacity in community means empowering people to build on their strengths and passions, to get involved locally in whatever way feels best, to support each other, include each other and learn from one another. People living with dementia, then, feel seen, heard, and appreciated as social and cultural contributors to society—a key to well being for us all.

Get Inspired

Check out how communities around the globe are building capacity for dementia inclusivity. Here are a few examples we love:

- [Momentia in Seattle](#)
- [Dementia Australia](#)
- [WestView Dementia Collaborative](#) (Dementia Connections Resources)
- [Alberta Health Services](#) - Innovations in Dementia Care

For more information, check out the project website at: buildingcapacityproject.com, or contact Community Research Coordinator Diana Cochrane at diana.cochrane@mhlp.ubc.ca.

Guiding Principles

Informed by research in the health and social science fields, as well as the experiences of those living with dementia, two key principles guide the Building Capacity Project:

Social citizenship. This means full access and inclusion for people living with dementia to participate in political, social, and civic life.

Asset-based community development.

This means building supports from the ground up (rather than the other way around) using strengths and capacities already in place.