

BUILDING CAPACITY PROJECT

At its core, "The Building Capacity Project" is a grassroots initiative that aims to enable people with dementia to participate in community life as full social citizens. We use an asset-based community development (ABCD) approach to support the growth of innovative community initiatives that foster inclusion and reduce stigma by creating meaningful opportunities for people with dementia to remain active and socially connected.

Watch the BCP Short Documentary

This project began as a cross-Canada partnership between researchers at the University of British Columbia and Lakehead University, and members of the Westside Seniors Hub in Vancouver and the North West Dementia Working Group in Thunder Bay. The four-year project was one of the first to launch under the Public Health Agency of Canada and its new, federally funded Dementia Community Investment Strategy.

After four years of collaboration, connection, implementation, and evaluation, we've developed a body of knowledge we'd like to share more widely. So, phase two of this work starts now with the development of an Action Guide. Project lead researchers, community partners and advocates living with dementia are working together to create this important working document that will help people in different locations, industries, and contexts start their own initiatives, become more inclusive, and build the advocacy and inclusivity climates to help us all expand our knowledge and our capacity. We're working with original community partners to sustain and deepen their work, and we're working with a new set of communities to help them establish their own initiatives.

Follow our newsletter for the most recent updates on what we're up to, and stay tuned for social media campaigns, webinars, and community networking events coming soon!

While the project engages two distinct communities in BC and Ontario, together these communities unite under three shared objectives:

- Implementing an ABCD approach to adapt and create community programs and services that are meaningful and inclusive for people with dementia.
- Conducting a developmental evaluation that will allow the team to learn how to best support the growth and integration of programs and services that are meaningful and inclusive for people with dementia.
- Disseminating learnings to increase awareness and to support communities and their efforts to create opportunities for meaningful participation by people with dementia.

The Building Capacity Project is not just about community organizations developing a whole new set of separate programs and services for people with dementia. It is also about figuring out a sustainable process for adapting and creating meaningful programs and services that are inclusive for people with dementia. We want more people with dementia to be active and participate in their community in a variety of ways, but more importantly, we want increased capacity in our communities so this kind of active participation can continue to grow and flourish.

Our Logo

Our logo represents connection, transformation, and joy. The text within the circles, captures the sense of belonging we feel connecting with people who share our values. The interwoven circles signify the unity of diverse communities in different places and spaces, illustrating how support and advocacy bring about transformation. Additionally, the three colors -indigo, light blue and red- represent distinct communities and individuals and the joy that comes from sharing a collective purpose.

ABOUT THIS PROJECT

The Building Capacity Project develops and evaluates effective ways to create sustainable opportunities for people living with dementia, and family/friend caregivers, to remain active and connected in their communities. Researchers at University of British Columbia and Lakehead University have partnered with community organizations to develop and evaluate supports and sustainable programs that help achieve this goal.

In Thunder Bay, Lakehead University has partnered with the North West Dementia Working Group (NWDWG). In Vancouver, University of British Columbia has partnered with the Westside Seniors Hub (WSH). This project is driven by and is for people living with dementia.

To improve the wellbeing of people living with dementia, the Building Capacity project will develop initiatives in the areas of arts, social participation, fitness, and volunteer activities. The project may also seek to adapt current resources (e.g. libraries, congregations, programming in community or seniors centres, etc.) to make them more inclusive of people living with dementia. Overall, we hope to support the growth of innovative community initiatives that will foster inclusion and reduce stigma by creating opportunities for people with dementia to remain active and socially connected.

The project is using an asset-based community development approach to move ideas into action in the two communities, in a way that respects the distinctive challenges and strengths in each. At the same time, we are using a developmental evaluation so we can adapt and sustain the initiatives as we go along, and capture learnings about

common underlying principles contributing to successful innovation. Using an integrated knowledge exchange approach, we will share our learnings more broadly so they can be scaled out more broadly over time.

Based on key learnings about what works, we will create a series of “how to guides” or other practical toolkits for communities wanting to implement similar initiatives to engage PLWD.

This project is a part of the Dementia Community Investment strategy funded by the Public Health Agency of Canada.

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.

The learnings we have gleaned from the first four years of the project are now informing the development of our Action Guide, a roadmap for other communities wanting to create more dementia-inclusive programs and services in their own contexts. As we build and share this document, the hope is that in addition to guiding other communities doing similar work, it will also inform policies and priorities in higher level community and health settings such that we completely shift the paradigm, erasing stigma from the conversation, and helping society share our view of dementia as a way of living in community.

Who we are

UBC’s Dr. Alison Phinney and Lakehead University’s Dr. Elaine Wiersma partnered with community leaders in Vancouver and Thunder Bay respectively on the Building Capacity Project. Both sites featured a research team and coordinator paired with a “backbone” community group. The backbone group worked closely with other community groups, organizations, and people with lived experience to form an interconnected web of support. In Vancouver, the Westside Seniors Hub served as the backbone. They are a highly committed group of volunteer professionals connecting people and organizations, spreading word about program offerings. Thunder Bay’s backbone was the North West

Dementia Working Group. Comprised of passionate volunteers all living with dementia, the NWDWG was uniquely positioned to listen to, hear, and advocate for people with dementia.

The two teams distributed seed funds and nurtured dementia inclusive opportunities in their communities. The results were inspiring: though each site launched from a different place and context, they both engaged people with dementia and related community organizations in different ways and acted as inspiration for other communities across the country. A rich variety of programs, community ties, and insights about the process emerged in both sites.

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 ran through to the end of 2023, at which point we received extended funding to develop an Action Guide based on all that we learned in those four years.

As of September 2023, a cross-province Community Advisory Team has been established, including researchers, community partners, and advocates with lived experience of dementia. This committee will oversee the development of the guide, offer suggestions, insights, and perspective to a) ensure the working document and all its suggestions centre the voices of people with lived experience, and b) identify the practices and principles that centre those voices throughout the community.

Our Process

Community Action Highlights

Vancouver

- The Westside Seniors Hub facilitated projects through several unique organizations. Examples include:
- A park bench project, which mapped 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 cafe 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 Northwest 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

Tracking our progress

For the first four years of this project, The Building Capacity Project facilitated, supported, and observed the community-led dementia inclusive programming in Vancouver and Thunder Bay. Through a developmental evaluation approach, the team learned a great deal about how best to 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 helped partners move forward. The Thunder Bay team really saw the benefits of a long-term process that built from the base of the North West Dementia Working Group, which was already established prior to the formal start of the Building Capacity Project. Together, the two teams shared learnings about how to create synergy between lived experience and grassroots community organizations.

Now that we’ve received an extension to our funding, we plan to proceed in two ways:

- Develop an Action Guide, co-written by a committee of researchers, community partners, and advocates with dementia.
- Expand our community partner support program. Community Research Coordinators and training specialists will be reaching out to other regions of the provinces excited to grow their dementia inclusive programming and culture, as well as deepening their work with existing partners.

Impact of COVID-19

The pandemic meant the closure of many community programs during the first phase of this project. But galvanized by the vision of more inclusive communities for people with dementia, both the Vancouver and Thunder Bay teams *endeavoured to pursue their goals and plans despite the obstacles. 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 timeline 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.

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.

COMMUNITY PARTNERS AND PROJECTS

Phase 2

Sunshine Coast resource centre and Gibsons seniors centre

Sunshine Coast Resource Centre (SCRC) is a “one stop shop” for community, social, and government services located in Sechelt, BC. They provide programming, information, and referrals in their community, and have formed a working partnership with Gibsons Seniors Society (GSS) who operates out of Harmony Hall in Gibsons, BC. Gibsons Seniors Society is “a volunteer organization, with several hundred members... [They] provide activities, services, and resources to support the health and well-being of seniors in their local community.” The two groups have banded together to make their community and the activities it offers more inclusive of people with lived experience of dementia.

[Visit their website](#)

Dunbar Residents Association

The Dunbar Residents Association piloted several dementia-focused initiatives during phase one of the project, including a gardening workshop series, a project known as The Fireweed Club (on which they collaborated with South Granville Seniors Centre, and Kits Neighbourhood House), and a neighbourhood asset mapping project that laid out where parks and park benches in the area were located to encourage seniors to get out safely for walks and visits during COVID lock downs. They plan to pick up where they left off for phase two, increase capacity through recruitment of people with lived experience and other volunteers, and shift the conversation about dementia to more of a community focus, reducing stigma in the process.

[Visit DRA website](#)

South Granville Seniors Centre

South Granville Seniors Centre has taken on several programs and initiatives to help create safe spaces and social engagement for people living with dementia. Their most notable one is the Happy Memories Café. This is a space where both people with dementia and their loved ones can meet to socialize, learn, and have fun together. The program activities evolve based on the ongoing feedback of participating members, and may include expert engagement, group discussions, music, poetry, and the arts. Everybody is welcome to participate and South Granville Seniors Centre hopes to be able to offer a Spanish speaking group. SGSC was a community partner in phase one and they are eagerly continuing into phase two!

[Visit SGSC website](#)

Kitsilano Neighbourhood House

KNH was a community partner in phase one of the project and is equally committed to phase two. They hosted an intern from the Netherlands in 2022 named Iris Brouwer who organized an intergenerational storytelling event that was a huge success. It was an “everyone welcome” event geared at kids featuring author Fiona Tinwei Lam who read her book “Rainbow Rocket” and spoke about themes of memory loss in an age-appropriate way. Feedback was overwhelmingly positive.

[Visit KNH website](#)

[Projects](#)

Purple Angels

The Purple Angels is a unique, Maple Ridge, BC-based support and activity group for people living with dementia and their families. The group's founder and facilitator, Myrna Norman, who has been living with dementia for over thirteen years, created the group based on the Purple Angels Global principle that dementia is not a single person issue; it's a family and community issue affecting more than just the person with the diagnosis. The group does a wide variety of activities together including some educational discussion, outings to cultural and social destinations, and seasonal celebrations like Oktoberfest and Chinese New Year. They've been gathering twice a month in the common room of Myrna's Fraser View seniors' complex for years and recently Myrna added two more groups into the mix for a total of six sessions per month. The two newer groups are steadily growing.

[Visit Purple Angels website](#)

Burnaby Neighbourhood House

Burnaby Neighbourhood House (BNH) is a community-driven, community-funded agency whose goal is to create more inclusive spaces within their programming for people with dementia and for those experiencing mental health issues. Their monthly Dementia Friendly Café is a two-hour event, hosted at two locations. It offers social time, educational presentations, and a variety of therapeutic activities, as well as support both for people living with dementia and their care partners. Their Seniors' Memory Club happens three times a month and is a less formal opportunity for people with lived experience and their care partners to enjoy social and exercise activities and have fun. Lastly, they run a day program for people who are further along in their journey with dementia. As a new community partner with the Building Capacity Project, their plan is to create a strategy for rolling out consistent dementia education across the region.

[Visit their website](#)

A.S.K. Friendship Society

ASK Friendship Centre was a community partner in phase one of the project and is committed to continuing the work in phase two. This adult day centre plans to expand cultural connections, recruit more volunteers, increase creative programming offerings and carry on with their van rental program.

[Visit ASK website](#)

Phase 1

Westside Seniors Hub (WSH)

The Westside Seniors Hub (WSH) is a volunteer community organization led by a senior Hub Council located in the Westside of Vancouver. The WSH formed a collaborative community partnership with the Building Capacity Project's Vancouver research team for phase one of our project called Dementia Ventures. Their focus was ensuring effective collaboration and knowledge exchange between 14 partner organizations who were planning, implementing, and evaluating new grass-roots social programming initiatives aimed at building meaningful participation by people living with dementia. They were a vital hub for the partners through those first four years and they continue to support and connect community groups throughout the Westside to date.

[Visit WSH website](#)

Projects

West Point Grey United Church

West Point Grey United Church got involved with The Building Capacity Project near the end of Phase One, hosting a series of workshops on brain health and memory loss in both English and Mandarin for their bi-cultural congregation, as well as organizing several Dementia Ventures training sessions using the Flipping Stigma Toolkit as a jumping off point. They have come on board as an official community partner in phase two of the project and will be working closely with our Community Research Coordinator and the rest of the BCP team to grow their dementia inclusive programming going forward. They hope to incorporate support groups and continuous dementia training into their community.

[Visit their website](#)

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Pacific Spirit United Church

Congregation members at Pacific Spirit United Church worked as a committee to create an insightful four-part series looking at dementia from a community perspective. It’s called Beacon *shining light on Dementia, and it is available online. One of their team members, Sabina Harpe, attended our project celebration in March 2023 to share some of the other initiatives they had developed including an additional online series focused on growing old (Beacon *shining light on growing old), “Books and Bistro,” a unique book club open to members of their community, and a special book collection in the church library focused on aging.

[Visit their website](#)

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[Visit ASK website](#)

THE TEAM

Staff Members

Alison Phinney, PHD, Academic Lead, UBC

Dr. Alison Phinney is the Principal Investigator of the Building Capacity. She is a Professor and the Associate Director of Graduate programs at the University of British Columbia, School of Nursing, as well as the Co-Director of the Centre for Research on Personhood in Dementia. She is an expert in dementia, with her work highlighting the potential for people to live well with the disease and as active members of their communities, bringing hope and understanding to families and society. She works in partnership with community leaders and people with lived experience to build knowledge and capacity for supporting personhood and social citizenship of older people, especially those living with dementia and their families. She has demonstrated the importance of social involvement and creative and physical activity for supporting well-being and personhood in dementia. Email: alison.phinney@ubc.ca

Andréa Monteiro, PHD, Community Research Director, UBC

Andréa Monteiro is the Community Research Director for the Building Capacity project for the Vancouver site. She works alongside people who live with dementia to engage and support community groups and organizations to imagine possibilities of inclusion and meaningful participation of people living with dementia and their care partners. Andréa has a PhD in nursing and is a documentary filmmaker, and her scholarship and filmmaking address social justice issues. She has twenty-three years of community leadership and engagement through the non-profit sector and fourteen years of work between nursing research, education, and clinical palliative care practice. Alongside her role with the Building Capacity Project, she holds a Research Associate position at the University of British Columbia, in the traditional, ancestral and unceded xʷməθkʷəy̓əm (Musqueam) territory. Email: andrea.monteiro@ubc.ca

Eric Macnaughton, PHD, Project Manager, UBC

Eric Macnaughton is the Research Manager, responsible for overall management of the project, and coordinating the implementation of new dementia initiatives across the two sites, as well as the research and evaluative aspects of the project. He has a Ph.D. from the UBC Interdisciplinary Studies program, has completed graduate training in community psychology, and has twenty-five years of doing community-based research, evaluation, and knowledge translation in the field of community mental health. Most recently he was involved in the At Home/Chez Soi project, an initiative to implement, evaluate and scale out a model for providing housing and supports for previously homeless people who deal with mental health and addictions issues. His interest in dementia stems from his family background and with the similarities in the mental health's recovery movement and the aims of this project in building social citizenship for people living with dementia. Email: eric.macnaughton@ubc.ca

Ania Landy MS , Community Research Coach, UBC

Ania Landy is the Community Research Coach for the Building Capacity project for the Fraser/Sunshine Coast site. Ania supports organizations and communities to address

inclusivity and stigma related to people with lived experiences of dementia and their care partners. Ania has a Bachelor of Therapeutic Recreation, and a Master of Science in Health Sciences, and is currently a PhD student. She has over 10 years of experience collaborating with diverse communities on community-based participatory research initiatives. She is passionate about supporting innovative and creative community work that addresses critical social issues, with a specific focus on aging and dementia. Her research interests include an intersectional approach to understanding health inequities and promoting cultural change in the care of older people, within both community and institutional settings. In addition to her role on the Building Capacity project, Ania holds a faculty position at Douglas College in the Department of Therapeutic Recreation. Email: ania.landy@ubc.ca

Paulina Malcolm, Community Research Coordinator, UBC

Paulina Malcolm is the Community Research Coordinator for several community-based research projects focused on addressing dementia-related stigma and promoting more dementia-inclusive spaces. She works closely with people with lived experience to better understand their social landscape, co-create research priorities, and support greater project engagement. Paulina has experience working on participatory action and co-design research projects in the field of dementia and older-adult mental health. She is interested in learning more about how to effectively collaborate with various community stakeholders and understanding new ways of doing research.

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Heather Neale, MFA, Knowledge Mobilization Lead, UBC

Heather Neale Furneaux is the Knowledge Mobilization Lead for the Building Capacity Project, and she has been working in collaboration with the Flipping Stigma Action Group as well. She develops knowledge projects, coordinates webinars and planning sessions, and works in close collaboration with the team's Visual Communication Designer to produce social media campaigns and other stigma reducing initiatives. She also helps with media coverage and project promotion. Her background is in writing and teaching. She's written for a wide variety of newspapers and magazines, as well as developing corporate content and advertising packages over the years. Her writing often investigates the impact of trauma on identity and she's a big fan of covering social justice issues, making use of storytelling as a vehicle for social change.

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Samantha Pineda, MFA, Visual Communication Designer, UBC

Samantha is the Visual Communication Designer of the Building Capacity Project. She works with researchers and dementia advocates developing tools, multimedia campaigns and visual solutions that translate concepts into appealing designs for various mediums, including film, digital platforms, print, branding, animation and more. In addition to her role at UBC, she is also a filmmaker and the co-founder of a

multimedia production company that focuses on storytelling in different media art forms. Along her career, Samantha has work with agencies and international brands directing commercials and advertising campaigns for Mexico and Latin America. She has also worked with different arts, culture and film organizations promoting visual literacy and local cinema. She has been an instructor and a consultant in accelerator programs for young filmmakers and a jury in diverse film festivals across the country. She holds a BA in Science Communication and an MFA in Film Production and Creative Writing from UBC. Email: samantha.pineda@ubc.ca

Elaine Wiersma, PHD , Academic Lead, Lakehead University

Elaine Wiersma is the Director of the Centre for Education and Research on Aging & Health, and an Associate Professor in the Department of Health Sciences at Lakehead University. She has completed her Master's and PhD at the University of Waterloo. Having spent many years working with older adults in practice and research, particularly individuals with dementia, Elaine's research aims to tell people's stories in ways that challenge stereotypes and misconceptions of older people, particularly persons with dementia. Advocacy, inclusion, and rights form the fundamental values underlying her work with people with dementia. Using participatory qualitative methodologies, her research spans community and long-term care, exploring aging and dementia care, contexts of rural and northern communities, and quality of life issues.

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Nisha Sutherland, Co Investigator, Lakehead University

Nisha Sutherland is an Assistant Professor in the School of Nursing at Lakehead University and research affiliate at the Centre for Education and Research on Aging and Health (CERAH). Focusing in the areas of gender, aging, and health, Dr. Sutherland critically analyzes how social relations shape health and health care experiences for people with chronic life-limiting illnesses. Building from her doctoral work, the focus of her research examines how the social determinants of health (e.g. geography, class, age gender, or race) intersect to shape health care experiences, particularly for people who are disadvantaged. Email: nsutherl@lakeheadu.ca

Carlina Marchese, Knowledge Broker, Lakehead University

Carlina Marchese is a Knowledge Broker for the Dementia and Seniors' Mental Health division at the Centre for Education and Research on Aging & Health at Lakehead University. She previously was the Research Coordinator for phase one of the Building Capacity Project in Thunder Bay, Ontario. She works in close collaboration with the North West Dementia Working Group. Carlina has a passion for gerontology and working with the elderly, especially people living with dementia. She has experience working in research, as well as front-line work with seniors. She holds a Specialized HBA in Psychology and a Master of Health Sciences degree.

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PEOPLE WITH LIVED EXPERIENCE

Myrna

Myrna lives in Maple Ridge, BC. After she was diagnosed in 2009 with Frontal Temporal Dementia, feeling total and absolute despair, her daughter Sherry explained to her, 'It is what it is'. At that moment, Myrna decided to become educated in neuro-cognitive disorders, and to become an advocate. Myrna's advocacy is far reaching as she speaks on the topic with the Purple Angel Ambassadors, the Alzheimer's Society of BC, various churches, and staff and residents of retirement and long term care homes. She recently also attended the Dementia Strategy Conference in Ottawa.

Speaking from personal experience from diagnosis, appointments, tests, appointments, and more tests, opened Myrna's eyes on the vast issues within the current care systems. Her belief is that we can all do so much more for our complete community of neuro-cognitive disorders, and it drives her to ensure that the therapies, education, long and short term care practices by staff are all well versed and aligned in the care required, and that offer answers and paths to a fruitful life.

Lynn

Lynn Jackson was born in Richmond, British Columbia and is a proud member of the Sauteaux or Plains Ojibwe, sometimes referred to as the Anishanaabe. She began her career as a Registered Nurse at the Royal Jubilee Hospital in Victoria, BC where she completed her education. She then worked at Toronto General Hospital for several years before moving to Mexico City (and later Puerto Rico) in the early 90's to pursue a job on the sales and promotional side of medicine. Lynn learned Spanish, joined a social running group, and made many lifelong friends there, several of whom she still connects with regularly. It was while living in Puerto Rico that she noticed something had changed for her and she pursued medical treatment resulting in a diagnosis of frontotemporal dementia.

Since then, Lynn has participated in numerous Alzheimer's Disease International working groups helping its member countries become more inclusive of people with dementia. She is one of the founders of Dementia Advocacy and Support Network International DASN (2001), the world's very first internet-based organization by and for people diagnosed with early-stage dementia. While DASN's website is no longer live, many of its members are still very involved in advocacy roles around the world, continuing to build on the momentum of what they started. And Lynn is no exception! She works with UBC's IDEA Lab on projects like their Telepresence Robot Study and Calm Robot Study, a study called "Implementing Dementia-Friendly Care for Cancer Patients Living with Dementia," and another called "Learning Health Systems for Dementia Care Transition." Lynn is a vital member of the Flipping Stigma Action Group, also through the University of British Columbia, and an End-of-Life Project through the

University of Waterloo. She's collaborating on "Innovation for Indigenous-led Dementia Care to Enhance Safety" through the University of Calgary, and she co-wrote an academic journal article with Dr. Lillian Hung for Perspectives called, "The Story of Elder Alex, A Reflection on Gerontological Nursing Competency Standards." She also served as a key research consultant for widely celebrated author Lisa Genova in the writing of the book "Still Alice" (later made into a critically acclaimed film starring Julianne Moore, Kristen Stewart and Alec Baldwin.)

Long-time Alzheimer's Society of BC staffer Barbara Lindsay described Lynn as "a dear friend, an effective advocate, and a wise volunteer."

Lynn's current interests include advocating for people with dementia and increasing awareness of Alzheimer's disease and related dementias. She has spoken locally, nationally, and internationally to promote better diagnosis, access to treatment and inclusiveness. Lynn has taken a particular interest in breaking the stigma surrounding a dementia diagnosis, and can be found speaking on panels, giving speeches and presentations, partaking in online discussions about outreach, and attending zoom meeting after zoom meeting for research and planning related to improving the quality of life for people living with dementia. She is a world traveler, a fierce and fearless advocate, and a vibrant and brilliant friend to those of us lucky enough to know her.

Bill

"I have always felt that a diagnosis of 'Dementia', should not stop a person from doing what they love to do for as long as they can continue to do it. "

Bill Heibein, formerly employed as a CA, has been living well with dementia for 20 years. He has not let his diagnosis stop him from continuing his active and social lifestyle--Bill owns and runs Amethyst Farms outside Thunder Bay, and he plays bass with local band Bottom of the Barrel. Bill is a self-advocate for people living with dementia, is a member of the North West Dementia Working Group, is a member of the advisory committees for the Alzheimer Societies of Ontario and Canada, and has worked on numerous research projects with Lakehead University and the University of Waterloo.

Bill is proud of his children and grandchildren and is proud of his ability to remain independent after receiving his Alzheimer's diagnosis in 2000 despite doctors telling him to go home and get his affairs in order, that with such an early diagnosis he would have to take medication immediately and would be lucky to get 5 more "good years" of his life. Bill is proud to be part of the first group of four people with a diagnosis of dementia to ever appear in person before the Canadian Senate Review Committee when they were studying the status of dementia in Canada prior to issuing their recommendations.

Most of all, he is proud that he and his late wife Heather were able to have a life of 60 years together.

I think the key to a healthy and rich life is to stay physically and socially active. Running a farm and having horses and dogs means that I have a reason to get up and get going every morning. It also means that it does not matter if the temperature is + 40 or - 40, I spend at least a couple of hours outside seven days a week. The social activity keeps me in contact with and talking to people.”

RESOURCES

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

Westview Dementia Collaborative

Dementia Connection Resources. The purpose of the Westview Dementia Support Community initiative is to increase inclusivity and reduce stigma for community members affected by dementia. Building upon community partnerships within the health, social and business sectors, the collaborative works closely with clients and families affected by dementia to increase understanding of current barriers that limit opportunities to participate fully in their communities.

Dementia Action Alliance

This non-profit organization provides hope and help to individuals and families living with dementia and information about how to live proactively with dementia. They offer services and peer support including three weekly online discussion groups, two monthly podcasts, an online Resources Centre, a national Speakers Bureau and more. All efforts and activities by this charitable organization are shaped and informed by individuals living with dementia.

DemSCAPE

(Developing Supportive Neighbourhood-Built Environment to Foster Mobility, Engagement and Social Participation among Community-Dwelling Adults Living with Dementia) is an interdisciplinary community-based research project out of Simon Fraser University that aims to understand the steps communities can take to make neighbourhoods friendly for people living with dementia and their caregivers.

The DICE Toolkit

Dementia Inclusive Choices for Exercise (DICE) is an online resource created by researchers and people with lived experience out of the University of Waterloo. It's for exercise providers and people living with dementia, to ensure exercise opportunities are person-centred and dementia inclusive.

Flipping Stigma on its Ear Toolkit

The Flipping Stigma on its Ear Toolkit has been listed by the World Health Organization's Global Dementia Observatory Knowledge Exchange Platform as one of the top ten awareness and inclusion interventions in the world. It's an online tool for helping identify stigma and finding ways to respond.

Emily Carr University Health Design Lab

The Health Design Lab is a research and design centre at Emily Carr University of Art and Design. They use participatory design methods to catalyze, support and amplify initiatives that address complex health challenges.

The Canadian Dementia Learning & Resource Network

The Canadian Dementia Learning and Resource Network (CDLRN) is a knowledge hub that facilitates collaboration between community-based projects across Canada and amplifies their successes.

RaDAR

(Rural Dementia Action Research) is a research team out of the University of Saskatchewan aiming to improve the delivery of rural dementia care across the continuum: from early diagnosis and detection to end-of-life care.

Momentia

Momentia is a Seattle-based grassroots movement empowering persons with memory loss and their loved ones to remain connected and active in the community. The Puget Sound region is home to a variety of dementia-friendly opportunities offered by a growing number of community members and organizations.

Dementia Australia

Dementia Australia represents the more than 450,000 Australians living with dementia and the almost 1.6 million Australians involved in their care. They advocate for the needs of people living with all types of dementia, and for their families and carers. They also provide support services, education and information.

PODCASTS AND WEBINARS

Feb-March 2023

Challenges in Recruiting People with Dementia into Advocacy Roles

Vancouver Island-based Lynn Jackson, a retired nurse living with Frontotemporal Dementia, joined Dr. Alison Phinney and Community Research Coordinator Dr. Andréa Monteiro in conversation about challenges around recruiting people with lived experience to advocacy roles in community support and engagement.

Nov 2022

Fear and Stigma in Dementia: A Dementia Dialogue Podcast

Dr. Alison Phinney and prolific BC based artist and dementia advocate Granville Johnson spoke about the fear and stigma associated with dementia, and the work they're doing to combat that. "People with dementia come from all walks of life. They're professionals: medical experts, lawyers, designers... They were world builders in their own right long before they were diagnosed with dementia. And those skill sets and talents are still there, but society tends to shut them out."

Nov 2022

The Case for Engaging People with Dementia in Community Efforts

The webinar discusses the asset-based community development approach we have taken to building out support for people with dementia, guiding our communities into a more dementia-friendly, inclusive way of being. Every initiative we tackle increases awareness and helps to combat some of the stigma associated with the condition. Stigma is one of the largest deterrents to living well with dementia.

Jun 2020

Programming Without Walls: How to Get Outside Safely

This webinar discussion will highlight factors to consider when planning to move forward and begin reintroducing programming for people living with dementia and their caregivers, and creating opportunities for meaningful participation.

May 2020

Through Our Eyes: A Presentation by People Living with Dementia and Care Partners on Stigma & Interacting with People with Dementia

This webinar presentation was developed and presented in partnership with people with dementia and care partners. We will discuss the appropriate language and communication to use with people living with dementia, as well as the associated stigma. This discussion can inform interactions with people living with dementia during the current environment and beyond.

WHAT WE'VE LEARNED SO FAR

Building capacity for people with lived experience of dementia achieving and sustaining impacts.

On this section, we outline the impacts of the Building Capacity Project at the individual and organizational levels, as well as learnings about key implementation principles, which we will draw on during the project's next phase to sustain and build on these impacts. We also describe a specific initiative to build knowledge and skill around dementia through the Flipping Stigma toolkit.

What were the aims of the building capacity project?

The overall Building Capacity Project objective was to enable people living with dementia to participate in community life as full social citizens. Towards that end, the project developed and evaluated effective ways to create sustainable opportunities for people living with dementia, and family/friend caregivers, to remain active and connected in their communities through various initiatives as planners and participants.

In Thunder Bay, Lakehead University has partnered with the North West Dementia Working Group (NWDWG), an action group of people living with dementia and care partners.

In Vancouver, University of British Columbia partnered with the Westside Seniors Hub (WSH), a network of seniors-serving agencies, and more recently the Flipping Stigma Action Group (an action group of people with dementia from across BC). Overall, our hope was to support the growth of a diverse range of innovative community initiatives that foster inclusion and reduce stigma by creating opportunities for people with dementia to remain active and socially connected.

Part One: Impacts

What did we achieve?

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

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

Members of the NWDWG, as well as some of the BC-based advocates (i.e. members of the Flipping Stigma Action Group) have also valued their involvement as educators for the Westside Seniors Hub, helping Hub partners make their settings more inclusive. These partners (community centres, neighbourhood houses, residents' associations, senior centres, church congregations, libraries, and seniors' day programs) have

described the value of learning from the Action Group advocates as well as from their Flipping Stigma toolkit. This has motivated them to learn more about dementia and its experiential aspects, including stigma, which has helped them become more confident and able to create supportive environments for people with dementia in their own settings. (See below for a description of the Flipping Stigma training initiative.)

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

What are the ongoing organizational impacts of the building capacity project?

The Building Capacity Project (BCP), in collaboration with community partners in Vancouver has developed (and in its next phase is endeavouring to sustain) initiatives in the areas of arts, social participation, fitness, and volunteer activities (such as Happy Memories Café, the Buddy Program, and pop up events through the Fireweed Club.) The Westside Seniors Hub, with the support of the BCP's communications team, developed a project-specific website and social media campaign (Soundbytes) aimed at the general public.

In Thunder Bay, the project built on previously established initiatives and created deepened opportunities for social participation through the Dementia Café, and opportunities for community advocacy through the North West Dementia Working Group.

Through the use of the Flipping Stigma Toolkit training, in Vancouver, the project has also supported community partners (e.g. libraries, church congregations, existing programs in community or seniors centres, etc.) to become more inclusive of people living with dementia by improving knowledge about dementia, raising awareness of the experience of dementia (including stigma) and increasing dialogue, thereby making community members, staff members and volunteers in these organizations more confident about being able to provide inclusive and effective support.

What were the impacts on specific subpopulations?

Though we collected some event-specific subpopulation data in the final phases of the project, we were not able to collect reliable quantitative data on gender and group identity factors that would summarize our project's overall reach for the entire reporting period. However, from qualitative data we can say that our main impacts here include the formation of the Dementia Sisterhood, a virtual support group for women with dementia including members from Thunder Bay, Vancouver, and a number of other provinces.

Another relevant impact in Vancouver came out of a three-part bilingual training event on dementia organized by the West Point Grey United Church that was conducted in English and Mandarin simultaneously, which increased dementia-related awareness, skills, and protective factors in the audience, including some people with dementia and care partners. (Evaluations of this training initiative, which was also conducted with other partners, identified further training needs in the areas of trauma-informed approaches to dementia and intersectional approaches to dementia). Also, as an offshoot of the Happy Memories Café, whose members include a majority of Spanish-speaking members, South Granville Seniors Centre is planning to develop a separate Spanish-speaking Happy Memories Café. Finally, as part of a cross-site event in October 2021, we conducted a series of panels on the influence of culture, language, and spirituality on dementia, and shared the learnings of these through SoundBytes, our social media campaign.

One key learning was that while stigma may be more prevalent in certain communities, people from racialized communities can find it more difficult to navigate the dementia-care system and access help.

Part Two: Implementation

How did we achieve these impacts?

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

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

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

- drawing on existing resources (which can get around the problem of trying to do something “off the side of the desk”)
- looking for “small wins” (and not getting overwhelmed by trying to do too much)
- staying flexible (some of our smaller partners were more able to move ahead during the pandemic, drawing on grassroots neighbourhood relationships)
- using a “ready, fire, aim” approach (not trying to have everything figured out, but moving ahead on something and then reflecting)
- the importance of having a champion at a high level of the organization

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

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

Learning about how to support implementation

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

The key elements of the approach, include:

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

REPORTS

April 2024

The Building Capacity's Project's
Phase Two Networking Event

April 2024

The Building Capacity's Project's
Baseline Interviews Preliminary Report

April 2023

The Building Capacity's Project's
Impacts and Learnings about Implementation

2022

Dementia Ventures
Partners Roundtable Takeaways

December 2021

The Building Capacity Project's
Developmental Evaluation Report Phase 1

Fall 2021

Building Capacity for Meaningful Participation for people living with dementia
Launch Conference Report

UPCOMING EVENTS

A list of upcoming events for 2024.

NEWSLETTERS

*Download the pdfs of each newsletter on the website.

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ACCESSIBILITY STATEMENT

The Building Capacity Project is committed to providing a website that is accessible to the widest possible audience, regardless of circumstance and ability. We aim to adhere as closely as possible to the Web Content Accessibility Guidelines (WCAG 2.0, Level AA), published by the World Wide Web Consortium (W3C). These guidelines explain how to make Web content more accessible for people with disabilities. Conformance with these guidelines will help make the web more user friendly to everyone. Whilst the Building Capacity Project strives to adhere to the guidelines and standards for accessibility, it is not always possible to do so in all areas of the website and we are currently working to achieve this. Be aware that due to the dynamic nature of the

website, minor issues may occasionally occur as it is updated regularly. We are continually seeking out solutions that will bring all areas of the site up to the same level of overall web accessibility.

If you have any comments and or suggestions relating to improving the accessibility of our site, please don't hesitate to contact us at samantha.pineda@ubc.ca. Your feedback will help us make improvements.