



Baseline Interviews Preliminary Report

Between November 2023 and February 2024, we conducted interviews with our B.C. community partners to identify their current plans, goals and potential challenges. Members of each organization shared their thoughts and insights with us, which will help us evaluate the progress of the Building Capacity Initiative as it evolves, and identify ways to better support all community partner projects.

Below are some of the themes that emerged from the first round of interviews with B.C. partners:

Using the D-Word: Challenges engaging people around the topic of dementia

Community partners discussed some of the challenges they faced engaging people with dementia in the community. One challenge community partners are grappling with is how to identify and reach people living with dementia in the community. Some found it difficult to find people living with dementia who have been diagnosed with the disease and are interested in participating in dementia-related programs. For example, Andrea from the Dunbar Residents Association commented: *"How do you reach out to find out who else in your neighbourhood is actually at home living with some level of dementia?"* To address these barriers, some partners had, or were looking to establish, connections with service providers who can refer people to their programs (e.g., the Alzheimer Society, health providers and regional health authorities).

Another challenge relates to the stigma associated with the word dementia. Community partners expressed concern that people with dementia may be reluctant to share their diagnosis or participate in programs with dementia in the title. To address this, some partners have shifted to using broader terminology like *"brain health"* and *"memory programs"*. Another strategy is to gear programs towards the older adult population, while also striving to be inclusive of participants with dementia.

For example, South Granville Seniors Centre has developed dementia-inclusive programs, geared towards all older adults: *"All our programs are geared for everybody...so even if you have some sort of cognitive decline... we have the get up and go program and the osteo fit."*

Growing confidence: The importance of training and hearing from people with lived experience

Several partners described the path towards developing dementia-inclusive programs as a journey that required ongoing education and interacting with people with lived experience. Training was highlighted as an essential component of developing dementia inclusive programming.



Some participants discussed the importance of ongoing training for all staff and volunteers, regardless of whether they work directly with people with dementia:

“So now we require mandatory training for all volunteers, which is like 200 people. So we have this staff training last year [with Flipping Stigma]. And we had the discussion group. Having all this stuff to reflect and learn helped us to spread the word and make sure all populations getting the... Doesn't matter if it's kids – at some point they are going to have grandparents or neighbours.” (Thais, Kits Neighbourhood House)

Participants also emphasized the impact of learning from people with lived experience of dementia. During Phase One of the Building Capacity Project, West Point Grey United Church, Kitsilano Neighbourhood House and ASK Friendship Centre completed Flipping Stigma Training, using a training that was based on the Flipping Stigma toolkit, drawing on the experiences of people living with dementia, and involving Flipping Stigma Action Group member Lynn Jackson as a trainer. Following the success of these training programs, partners have expressed an interest in bringing in the Flipping Stigma Action Group for a presentation, and emphasized the impact of learning from people with lived experience.

Some participants had attempted to establish advisory groups of people with lived experience, but found it challenging: *“We couldn't start this group because we didn't have people. We mostly had caregivers. Some seniors we contacted didn't feel comfortable with something like that.” (Thais, Kits Neighbourhood House)*. In light of this setback, Kits Neighbourhood House opted to get feedback from individuals on a one-one-one basis, tailoring their Memory Buddy program to match each individual's needs. To guide their planning, the Dunbar Residents Association plans to form an action group that includes people with direct experience of dementia, including people living with dementia and their care partners or significant others.

Centering Joy

Another theme that emerged from the interviews was the importance of fun, enjoyment and celebration. Myrna, from Maple Ridge Purple Angels, summed up her overall approach to programming: *“What I really want is to help people live a happy life. They don't need to know about dementia if they don't want to. They just really need to live a happy life.”* In addition to prioritizing fun and joy, Myrna also emphasized the importance of celebration: *“Last year we had this celebration of people living with dementia, and we had it in our city park, right downtown...and the newspaper was really great about using the words ‘celebrating people with dementia’. That's my ultimate aim: to celebrate.”* Similarly, Farhad from Burnaby Co-Creation Academy commented at the Networking Event: *“Creativity is so important. Bringing some joy, creativity, art. Art is a missing piece in many projects. So please don't make boring programs!”* Celebration emerged in other ways too. For example, Kits Neighbourhood House hosts an annual volunteer appreciation event to ensure volunteers feel valued and have something to look forward to.



Utilizing assets

Community partners highlighted a range of assets they can draw on to grow and sustain their programs. Partnerships with service providers, neighbourhood associations, community groups and networks were viewed as essential. For example, several partners spoke about their connections to the Alzheimer Society. Several community partners, such as Burnaby Neighbourhood House, Kitsilano Neighbourhood House and South Granville Seniors Centre discussed receiving dementia education sessions from the Alzheimer Society. Other partners, such as the Dunbar Residents Association, expressed an interest in furthering their connection with the Alzheimer Society. Going forward, better integration across municipalities, health systems and the social services sector was identified as an important area of opportunity.

Staff and volunteer capacity emerged as core assets. Participants particularly valued having staff and volunteers with diverse skills sets, and those who speak multiple languages: *"We're blessed to have a lot of people in our Latin community that are bilingual that help us to speak to our people"* (Jennifer, SGSC).

Connecting with people with lived experience was also identified as a key asset. At the Building Capacity Networking Event, Academic Lead, Elaine Wiersma emphasized the value of engaging people living with dementia: *"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."*

Reframing Dementia as a Community Issue

Some partners discussed the importance of understanding dementia as a community or collective experience, rather than an individual or family problem. These conversations reframed dementia inclusion as part of the broader goal of community building, and as part of a strategy where care partners and community members were included in dementia-related programming.

For example, Myrna from Maple Ridge, described how her group, the Purple Angels invites care partners and neighbours to activities and events, and commented: *"Dementia is not a single person issue. It's a family, it's a neighborhood, it's a community issue."*

Similarly, Andrea from Dunbar Resident's Association, stressed the importance of broadening support for dementia programs and services: *"People were fine to go through other booths but once it came to dementia it was "oh that's not for me." It's still this topic that impacts many other families. It's about our community. And this is something that has impacted many in our community. I'm hoping that perspective can open a conversation."*