Cross Cutting Themes on the Implementation and Impacts of the Building Capacity Project, Phase Two

The case studies illustrated a number of cross-cutting themes connected to the process and impact of the project. These included:

- **a growing sense of co-creation,** including the active involvement of people with dementia and community members, and the positive influence of this approach in shaping how BCP Partner initiatives evolved;
- **the importance of strategic framing in relation to how Partners conceptualized their initiatives in relation to the term "dementia",** leading to a broader inclusive approach, together with a strategy for "changing the narrative" about dementia so this focus is not lost;
- **the value of a relational approach,** for program design focussing on creating connection, and for implementation, including through the formation of organic provider networks;
- **embracing complexity,** using the concept of "wayfaring" based on general principles or vision, to take advantage of emerging opportunities, rather than following a script and trying to achieve pre-determined outcomes; following a complexity-based approach partners also sought to influence the inclusiveness and responsiveness of their surrounding community (including the service system)
- **program impacts focussed on connection, enjoyment and purpose,** experienced by people with dementia, care partners, volunteers, as well as initiative leaders
- **an increased focus on sustainability efforts,** through strategic relationships with other funders (most particularly United Way), and through continued Asset-Based Relationship (ABCD) strategies, aimed at building a broader base of leaders, volunteers and other key resources

The evolution of an organic network of BCP Programs in expanding access to support, and supporting continued program development, which suggests the value of developing continued infrastructure for a Community of Practice to support and grow the work of the Building Capacity Project and its partner organizations "as part of something bigger."

Engagement as Co-Creation: enabling community driven leadership

Engaging the community has been integral to the Building Capacity Project. In Phase Two, we've witnessed strong community-driven leadership, as the various partners have moved towards a "co-creation" approach featuring a significant and increasing degree of participation and ownership from people with dementia, as well as from the broader community. This spirit of co-creation has manifested in various ways, as exemplified by the process for developing the Action Guide, which involved the involvement of project staff, community champions, and advocates with lived experience of dementia**.** **For the Burnaby-based Dementia Co-Creation Academy,** this ethos started with the initiative's formation, as the participants of a previously run program encouraged DCCA's leaders to begin a new one, and acted as an advisory committee during the new project's development. **For Kits House**, co-creation manifested as an increased sense of ownership adopted by the memory buddy pairs, as they moved beyond the original approach of "hanging out" once a week, and spontaneously started meeting more often, basing their choice of activities on individualized goals that the buddy supported the participant to develop.

The Sunshine Coast case study illustrates engagement of the broader community, as the initiatives' leadership team facilitated the involvement of Gibson's Senior Society's members through a survey, enabling their participation in the planning of a successful, well-attended workshop series that in turn, has shaped the subsequent evolution of project. As the workshops were implemented, community leaders nimbly drew on the ideas and resources of other community members, using a style of enabling style of leadership referred to "letting the doers do." **The ASK** transportation initiative also represented community ownership in the sense of the involvement of other community groups (funded agencies as well as grassroots groups, including other BCP Partners) who participated in the conceptualization of the initiative and who were able to successfully influence the evolution of the program as part of the steering group.

Partners' engagement with their communities also enabled them to respond to cultural considerations when planning and running their programs. **At SGSC,** the participation of multiple Latinx participants during Phase One led to the formation and solidification of the Spanish Speaking Memories Café during Phase Two. During Phase One, we witnessed cultural bridging strategies occurring, for example in the initiative of West Point Grey United Church to foster culturally sensitive (as well as inter-cultural) conversations about dementia within the context of their bilingual congregation whose members spoke English and Cantonese. Similarly, in Phase Two, the DCCA features a multi-cultural group whose members are from Chinese, English-speaking and Farsi-speaking backgrounds. The group's conversations and activities are responsive to this context, for instance, by employing on embedded volunteer translation as

needed, and featuring culturally-appropriate activities that resonate with members, e.g. the Farouz-themed event which celebrated the arrival of spring in Persian fashion.
Common throughout these cases is committed leadership that is well-embedded and responsive to their respective communities; this brings a well-founded sense of what's needed, as well as a reflective approach to understanding what's working well, and what adaptations are needed. In the case of SGSC, these qualities enabled the program's leaders to move beyond their program's initial focus on dementia-related education and move towards an approach that emphasized creating a regular opportunity for participants to socialize and enjoy themselves. This fits the experience of the founders and participants of Thunder Bay's Dementia Café, who learned to **"leave diagnosis at the door."**

Over time, through training and experience, communities gradually became more confident and expanded their sense of what was possible when it came to actively engaging people with lived experience of dementia in shaping program development. **In Phase One** of the project, this entailed organizing drawing on the North West Dementia Working Group (NWDWG) with established dementia advocates, and designing workshops based on the Flipping Stigma toolkit, featuring a lead role for Lynn Jackson, a BC-based dementia advocate. **In Phase Two,** we continued these workshops, further involving Purple Angels' leader Myrna Norman, whose message emphasizes how her own dementia journey was paved by people who empowered her to see that she was still entitled to enjoy life, and find a sense of purpose and connection. This philosophy guides her own peer support group, and has helped BCP partners conceptualize their initiatives similarly. As a staff member of the Burnaby Neighbourhood House stated after hearing Myrna: *"it's not about starting a program; it's about creating a community."* Partners are also expanding their sense of possibilities for active involvement of their own participants in shaping their programs, including the possibility envisioned by one partner that they could "find their own Myrna."

Strategic Framing of BCP Initiatives: changing the narrative about dementia

During their community conversations, and throughout the visioning and planning phases of their initiatives, partners often wrestled with how to conceptualize their initiatives in relation to **"the D-word,"** when discussing their initiatives' overall direction, and who their target audiences would be. Some, the like the Dementia Co-Creation Society, whose members were already comfortable with their diagnosis, included the word "dementia" in their title. Given the stigma and fear engendered by the term, most others framed their initiatives using terms considered safer, like "memory", and "brain health" where they anticipated that people could be more willing "see themselves," and more likely to participate. Examples included events around "brain health" organized by BNH and Sunshine Coast's 4-part "Managing Memory as you Age" series,

Purple Angels "Memory Café," SGSC's "Happy Memories" Café, and KNH's "Memory Buddies". With the exception of Purple Angels, these initiatives were more inclusive, and were aimed towards people with or without a diagnosis, who struggled with memory issues, or who were simply interested in prevention.

Regardless of terminology, another important shift has been to reorient the programs away from focussing on the individual, per se, towards supporting people to find belonging within their social networks, and to create new opportunities for community. This was exemplified by the Happy Memory Café approach already described, also by Myrna Norman's memory café, which follows the philosophy of the (worldwide) Purple Angels movement, framing dementia "not just as a personal issue but one with impact on the family and the whole community." Similarly, rather than focussing on an individual's memory loss, KNH's Buddy Program focusses on "creating meaningful interactions to address social isolation."

Importantly, such strategies are not simply about choice of words. As a participant in a BCP networking event remarked about the shift in the Memory Buddy program's title ***"this was about changing the whole narrative."*** Nor were they about avoiding the topic of dementia altogether, which in Phase One, we did note as a danger, when partners initially tended to use safe, generic terminology (e.g. "seniors programming") without being intentional about bringing dementia back into the conversation. **In Phase Two,** it has become clearer that in order to do that, these considerations around framing must also be part of broader strategy to create a safe space for changing the narrative around dementia. For example, in the Sunshine Coast the "Managing Memory" series included dementia-specific education from a local specialist physician, as well as a workshop led by Myrna Norman using the BCP Conversation Starter Cards, designed to create safe, experientially-based conversations. Similarly, the BNH events used intentional conversation starter strategies, including the cards, as well as other engaging ways to raise the topic of dementia safely, as participants played a brain-health themed version of "Family Feud" that also included dementia-specific content.

In addition to making the topic of dementia safer, these interactions were seen by participants as changing the perception of what it meant to have dementia, leading them to ***"seeing dementia differently...*** especially (after seeing) people with dementia leading community change," as noted by the Sunshine Coast participant after participating in the workshop led by Myrna Norman. This created a ripple effect as it became after for others to disclose, and was accompanied by a strengthened focus within that initiative to address the d-word head on and ***"take dementia of the closet."***

Adopting a Relational Approach to Program Design and Implementation

In Phase One, our Thunder Bay Partners from the NWDWG noted that *"the relationship is as important as the work."* During Phase Two the importance of adopting a relational approach to program design and development has come increasingly into focus in BC; as a SGSC participant put it, affirming Myrna Norman's message, and recognizing that *"people need to be together"*, and about *"seeing joy on people's faces"* as they participate and interact. Along these lines, new partners described how they avoided thinking in traditional program development. They affirmed learnings from Phase One about the importance of sharing a meal, and the value of a creating a vibrant space for community building. For Purple Angels, this included moving from the seniors centre (where participants experienced some stigma), into Myrna's home, meeting in restaurants, or having a picnic in a park during good weather while playing bocce ball.

Just as a relational approach was integral to program design, relationships were integral to ongoing program development, as BCP partners followed an Asset-Based Community Development approach, drawing on existing partnerships or building new ones in order to build their initiatives. This entailed volunteers, who provided peer support, artistic guidance, food; it also involved securing in-kind support from other organizations, such as training, mentorship, or supplementary supports. Success in doing so often related to the embeddedness of the organization within the community. For instance, in Maple Ridge, Myrna Norman's request she made at her municipal Health Aging group led to finding a new volunteer to help her organize her peer support groups. A well-connected leader in Gibson's when problem-solving how to meet a certain need, would inevitably "know a guy" who would help.

Also important, particularly when previous relationships were not as established, was finding partners with shared values or interests where there was some reciprocity rather than simply an "ask." This was illustrated by the formation of DCCA's partnership with the Rideau Retirement Residence, where DCCA secured a bright, accessible, street-level space with nearby parking, and the program was made available to residents of the care home. The sense of reciprocity derived by volunteers has enabled DCCA and other programs, e.g. KNH, to develop a growing pool of people, who no longer need to be recruited, but approach these programs to seek out opportunities.

Both of these initiatives have witnessed the emergence of a phenomena one partner referred to as **"volunteer families"**, including parents (the original volunteers) and their offspring who subsequently come on board. For instance, at DCCA, young volunteers have run program sessions (e.g. the creation of a memory blanket), and launched fund raising initiatives (e.g. a volleyball tournament), supported by a "project-based learning" framework that enables them to build their resume. At Kits Neighbourhood House, memory buddies are no longer only 1:1

relationships but in some cases feature broader support networks including more than one buddy, or support clusters including the original buddy, an offspring, and also grandchildren. Another related development is the fostering of relationships between Building Capacity partners, as a way to improve their own programs, and expand access to a more comprehensive range of supports to complement their own offerings. For instance, participants from KNH and SGSC have attended outings provided through ASK's Bus Program. The program itself was inspired from a pilot trip organized by Dunbar Residents Association, an original BCP Partner. In order to learn new approaches, the volunteer coordinator from ASK now attends DCCA as a regular volunteer. KNH and SGSC have partnered to obtain a successful United Way grants around information and referral and system navigation.

Embracing a Complexity-based approach to Implementation

Though program development is often conceptualized as entailing the establishment of a program logic model aimed at using specific steps to achieve pre-determined outcomes, within linear implementation stages, the BCP was founded on a developmental, complexity-based approach that was less linear and predictable.

As in Phase One, the approach could come with some initial anxiety, given the uncertainty or open-endedness about what the initiative was expected to achieve at the outset of their involvement. For instance, the Sunshine Coast Partners found "the start [of the project] very rocky" and "had no idea what to expect." However, this approach has borne fruit as it has allowed them to develop responsive approaches suited to their own community. **Over time, other BCP Partners have also come to appreciate the project's flexible approach to helping them plan and implement their initiatives.** In Phase One, faced with an initially ambiguous task, partners talked about the value of "trying things out", and adapting as they went along, and became more confident as they began to reflect on "small wins" and build on what worked. In a similar vein, partners **in Phase Two talked about the idea of "wayfaring"**, which meant following general principles, rather than a script, and being able to respond to and capitalize on new ideas congruent with this vision as they went along. The phenomena of family volunteering (and building intergenerational support networks) is one such idea that emerged with two of our partners who had adopted this mindset.

Another variation of the idea of embracing complexity was articulated by our Thunder Bay partners, who talked about the importance of benefitting from a convergence of unpredictable factors. Elaine Weirsma talks about how success for them has been associated with having the *"right people", and "the right place", come together at the "right time."* As suggested earlier, a complexity-based approach to program development entails an enabling style of leadership

("letting the doers do"), and avoiding what one leader called "a bureaucratic lens" that is overly focussed on managing risks, as opposed to taking advantage of opportunities. It also entails learning to move on when doors appear closed, for instance when a potential partner doesn't respond promptly or enthusiastically, indicating that the timing is not right, or, perhaps because of a mismatch of values, that it's not the "right partner."

A complexity-based approach also entails being sensitive to the surrounding context of the initiative, and taking steps to influence the "systems" in their surrounding community. For BCP Partners this means engaging with the broader community to address the stigma that hinders their own efforts, and makes things more difficult for their own participants in their wider social networks. For this reason, during Phase One, leaders from Westside Seniors Hub spearheaded the creation of a series of posters that continues to run on buses in BC's Lower Mainland. During Phase Two, various Partners have also participated in campaigns that raise awareness and challenge stigma amongst community members (e.g. fund raising walks). It has also meant helping their participants navigate the often confusing and inadequate system of community support for people with dementia. The Sunshine Coast is a good example here, as it's workshop on care giver support featured the involvement of a care partner whose motivation for attending was to help others going through a similar experience. Sunshine Coast leaders continue to strategize about how to further this "systems change" approach in the future, beyond their formal involvement in the BCP project.

In accordance with this complexity-based approach, In Phase One, one participant characterized their activities as "throwing pebbles in the pond" and watching the impact ripple out both within and beyond their own initiatives. This expression to continues to be an apt metaphor for the activities of BCP Partners in Phase Two as their initiatives have evolved in unexpected and serendipitous ways, and as their efforts have influenced their surrounding communities to become more inclusive and responsive to people with dementia.

Impacts

We conducted several focus groups to measure the impact of BCP initiatives amongst partners, which showed an impact on sense of belonging (including cultural belonging), engagement/ enjoyment, and feelings of support. Focus group participants indicated through their quantitative ratings (as summarized in the indicators section of the Final Report) that their participation made a significant difference with respect to each of these things.

Qualitatively, we also heard about how participants (including volunteers), also gained a strong sense of purpose that was connected to their involvement in the project, and to make a

difference in the lives of others. As also described above (under "other indicators", there was a significant impact with respect to the deepening of relationships between volunteers and participants, which included the formation of a strong and growing support networks that moved beyond initial 1:1 volunteer/participant relationships, and included an intergenerational aspect.

Sustainability

Sustaining the programs and extending their reach and impact was a main concern of partners throughout Phase Two, which manifested in various ways, including through the partnerships described involving United Way funding. Other strategic partnerships with the United Way's Community-Based Seniors Sector initiative have significantly contributed to the broader sustainability efforts of partners, helping them retain staff and resources to solidify and grow their initiatives. The ASK bus program was funded through United Way's seniors transportation initiative for one year and extended for another year at greater scale. Through the United Way's Caregiver Support stream, Kits House will continue and expand the Buddy Program, which will adda a care partner support component, through a one-year grant with the possibility of extended funding. Also through United Way funding, Burnaby Neighbourhood House, building from their experience with BCP, and using the new BCP Action Guide, will pilot a dementia-inclusive day program at one of their BC Housing sites. Purple Angels has received funding and in kind support that will allow them to use the Maple Ridge Seniors Centre space and resources to augment their programming.

As BCP partners embark on these expanded initiatives with new partners, they anticipate some issues in relation to in "staying true" to who they are within this new funding environment. For instance, Purple Angels partnership with the senior center may entail navigating the constraints of new rules, and a more formal social environment which may come with some stigma attached. In general, new funding sources may come with additional requirements around record keeping and data gathering that may be incongruent with the BCP's more flexible, developmental approach.

Throughout the two phases of the BCP, the project has benefitted from the commitment of leaders for whom the work has been and continues to be "a passion project." Sustainability in the sense of solidifying these programs has come from an ability to distribute leadership, including finding key point people to drive their initiatives. In Phase Two we've also witnessed a growing base of committed volunteers who help run and resource various programs. Going forward, the organizational culture and commitment to an Asset-Based Community Development Approach foster sustainability in this sense. From an ABCD perspective,

sustainability will involve continuing to build a base of volunteers, and fostering shared leadership, so that the programs can continue when the founders are no longer involved, original volunteers move on, and people with lived experience and care partners can no longer participate. The concept described by one BCP participant of sustainability as a "relay race" may be helpful, suggesting that community leaders make intentional efforts to draw in and mentor others as part of their ongoing work.

According to BCP Partners, sustainability efforts have also benefitted from the credibility of the BCP, as their involvement (and evaluation findings) has been cited in successful funding proposals, and BCP staff have provided direct support (e.g. evaluation and mentoring support) as they've implemented their expanded offerings. The credibility of the project has also been beneficial for asset-based strategies, and is expected to continue to offer benefits beyond the funded period of the projects for partners as they continue to develop new partnerships and resources. As one partner explained, it is easier to ask for resources by *"saying you are part of the UBC BCP project."*

Implications/Conclusion

As in Phase One, partners affirm the value of continuing to do the work "as part of something bigger", or as part of an overall movement where like-minded people and organizations implementing similar initiatives as part of a network. As described previously, this network has evolved organically as partners have come together to connect their current initiatives and develop joint funding proposals for further work. They also affirm the need for future resources for some infrastructure to continue this community of practice.