

A Public Health Agency of Canada Dementia Investment Strategy Project



Building Capacity for Meaningful Participation by People Living with Dementia

*Launch Conference Report:
February 2020/September 2020*

Acknowledgements

The event, and the learnings that flowed from it, would not have been possible without the thoughtful contributions from all who attended. The richness of insight and conversation was made possible by the active participation of all delegates, but especially by those living with dementia. Thank you for your time and energy and for sharing your experiences. The organizers also extend a sincere thank you to everyone who took the time and care to be involved, from event preparations to the dialogue on the event days.

Funders: Public Health Agency of Canada – Dementia Investment Strategy

Event Hosts: Alison Phinney and UBC Research Team
Westside Seniors Hub (WSH) Working Group

Community Leads: North West Dementia Working Group (NWDWG)
Westside Seniors Hub (WSH) Working Group

Research Leads: Alison Phinney, Professor, School of Nursing, University of British Columbia
Elaine Wiersma, Associate Professor, Health Sciences, Lakehead University

Building Capacity Team
Eric Macnaughton, Project Manager,
Diana Cochrane, Community Research Coordinator, Vancouver
Carlina Marchese, Community Research Coordinator, Thunder Bay

Centre for Education & Research on Aging & Health (CERAH)
www.cerah.lakeheadu.ca

Centre for Research on Personhood in Dementia (CRPD)
www.crpd.ubc.ca

Event Facilitation: Sarah Lusina

Report Preparation: Sarah Lusina & Eric Macnaughton



Funded by the
Government
of Canada

Canada

Workshop Report

Contents

Acknowledgements	0
Executive Summary	2
Background.....	6
The Project	6
The Workshop	6
Day One – Building Leadership Connections.....	8
Morning Tour – Highlights.....	8
Afternoon Dialogue – Highlights.....	9
Roundtable Reflections	9
Showcasing Communities – Structures & Settings	10
Collaborating with Researchers	12
Day Two – Engaging Community Partners & Sparking Inspiration	13
Opening Welcome	13
Keynote – Social Engagement & Dementia: The Lived Experience	14
Panel – Perspectives on “The Lived Experience”	15
Building Community Capacity for Social Citizenship: Momentia	17
Panel – Turning Ideas into Action & Success	19
“Making the Pitch” – Promoting dementia-friendly initiatives	24
Pair & Share Dialogue.....	25
Research Update	25
Capturing the Learnings	27
Successful features of dementia inclusive programming	27
Technical considerations for successful dementia inclusive programming	29
Closing Remarks	31

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Executive Summary

Background

The *'Building Capacity for Meaningful Participation by People Living with Dementia'* (or Building Capacity) Project is the first project to launch under the Public Health Agency of Canada and a new federal [Dementia Community Investment Strategy](#). The project engages two distinct communities: Vancouver's Westside through the Westside Seniors Hub (WSH) Working Group and researchers from University of British Columbia (UBC) as well as Thunder Bay through the Northwest Dementia Working Group (NWDWG) and researchers from Lakehead University.

At its core, the Building Capacity Project aims to enhance and promote opportunities for people living with dementia, including dedicated and inclusive physical and social activities that account for the interests and needs of people living with dementia. Galvanized by a 'bottom-up,' asset-based approach, the project fosters connections in community and the growth of initiatives¹ based on community capacity and interest. As initiatives take shape and unfold, the project team will use a developmental evaluation framework to capture the experiences, stories, and impact of these initiatives, and make real-time adaptations.

Recognizing that strong relationships within and across communities are essential to achieving the aims of the Building Capacity Project, the team prioritized a "project launch" workshop. Here, community-based leaders, advocates, formal and informal care partners, people living with dementia, and researchers would be able share their experiences and insights in designing and providing dementia inclusive programming. The workshop aimed to build capacity among those leading and supporting various aspects of the project by creating connections between people and ideas. Further, to guide project activities and to authentically acknowledge and integrate lived experiences with dementia, the workshop sought to surface the expertise of those associated with the project as well as their knowledge of community assets and needs.

Workshop Proceedings & Learnings

Day 1

The WSH, NWDWG, and research leads kicked off the first day of the workshop with a site tour of Vancouver's Westside and some of the WSH Partner organizations. The tour illuminated the significant influence of place on programming possibilities. Vancouver was at its finest for a February day. The sun was shining and early signs of spring were in bloom – a stark contrast to Thunder Bay where it was still snow covered. Participants noted that Vancouver streets are well serviced by transit and well designed for walking, especially with the backdrop of snow peaked mountains and a white capped ocean. In addition, there seemed to be many and different types of community-based organizations well positioned to take part in dementia inclusive programming. In contrast, Thunder Bay has limited transit options and streets are designed more for cars than foot traffic. NWDWG leads noted a lack of readiness of Thunder Bay's community-based organizations when it comes to dementia inclusive programming.

Despite differences in built, natural, and service environments, workshop participants noted that a common draw to any program in any community and for any age group was food. Sharing,

¹ In this report we use the term initiative, innovation, program, and opportunities interchangeably. The terms are used to mean a set of related measures or activities with a particular long-term aim of engaging people living with dementia in community life.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

socializing, and celebrating with food should not be forgotten as dementia inclusive programs are designed and enhanced under the Building Capacity Project.

Reflecting on the tour and their current approaches to dementia inclusive programming, NWDWG, the WSH Working Group, and research leads each shared the experiences and strengths that they bring to the Building Capacity Project. For the NWDWG, they bring strengths in participatory approaches to education and social action; experience in influencing and informing Ontario's Dementia Strategy; and a suite of training and outreach tools and approaches. The popular "I May Have Alzheimer's But it Does Not Have Me" t-shirt is example of how the NWDWG leads anti-stigma and educational outreach at the grassroots level. The Westside Seniors Hub brings broad reach with community-based organizations and their networked structure positions them well for collective action approaches to dementia inclusive initiatives. Their "Walk and Be Seen" campaign is an example of how quickly and how well a new initiative can be seeded, supported, and implemented by the WSH partner network. The researchers bring strong listening and documenting skills and are keen to help catalyze action and innovation and to help capture and communicate about "what works" well and why.



Alison Phinney & Elaine Wiersma, Research Leads

Day 2

In a dynamic series of facilitated sessions, the second day folded in the participation of community-based organization leaders, advocates, formal and informal care partners, and people living with dementia from the Lower Mainland and Seattle areas. To set the stage, Thelma and Art Stogan, Musqueam elders opened the workshop. They offered profoundly relevant messages for the Building Capacity Project. They reminded us of the importance of **place**, incorporating knowledge from our **past** into future actions, and the value of working in unity with others and our environments.

Inspired by the welcome, Myrna Norman offered a powerful keynote presentation that mapped her personal dementia journey, which moved her from grief into advocacy. She stood up against "prescribed disengagement" and sought active involvement. Myrna's story underscores the importance of **enabling those living with dementia to lead** dementia inclusive initiatives and advocacy work. Family, friends, and opportunities to participate in community play an important role in supporting people living with dementia.



Marigrace Becker

In contrast to Myrna's deeply personal story, Marigrace Becker's plenary presentation showcased the broad efforts of community organizations. In her talk, Marigrace shared her experience with **collective action and collaboration** that led to the formation of Momentia, a citywide movement to make Seattle more dementia inclusive. Momentia grew organically, over time, as staff from various organizations realized that they were running parallel initiatives and that their organizations held similar interests. Formal and informal networking was an essential element to the formation of Momentia as was the slow, natural pace of how the relationships developed.

Marigrace encouraged workshop participants to **think small before thinking big** and that small efforts can reveal bigger opportunities for action. She also underscored the importance of capitalizing on the natural

Workshop Report

energies and organizational capacities of the community using an **asset-based approach**. Building from what already exists is not only more sustainable over the long arch, but also positions the initiative for success in the immediate term.

The panel, breakout and dialogue sessions surfaced many innovative, productive, and meaningful ways to engage people living with dementia. Meal sharing, walking clubs, making and listening to music, making and critiquing art, supported volunteer tasks, and dancing were identified as enjoyable activities, based on the principle of **"go with what gives you pleasure"**. Numerous other concepts that should guide program development and implementation were identified. Like Marigrace, many of the 'Ideas to Action' panel presenters stated that programs are positioned for success when organizers **include people living with dementia in all stages of program development** – from design to implementation. When collaborators build on shared interests across organizations the community and the participants they are hoping to include benefit. In some cases, designing programs that are **inclusive across generations** and abilities is attractive for people living with dementia and adds a richness of interaction that is unique and meaningful.

Care partner participation in programming is critical. Depending on the activities, dementia inclusive programming cannot operate without the participation of care partners. Where people living with dementia can participate in programming without their care partners, building in a parallel and dedicated respite programming for care partners is not only practical but can be of benefit for both the person living with dementia and their care partner. Both parties need opportunities to have time apart from one another, be engaged in meaningful and fun activities, and be motivated to return. Another practicality to consider is the physical gathering space. **The space in which the program is offered can "make it or break it."** It is key to think critically about the kinds of space needed to operate certain kinds of programming. Programmers must think beyond the technical needs and consider the kind of "feeling" that the space offers.

Getting new initiatives off the ground can take time so identifying champions, being patient, and assisting with timelines and logistics can help foster success. As initiatives take shape, rooting them in an organization enhances **sustainability**. When integrating programming within organizations, panel presenters and workshop participants highlighted the need to be creative with solutions to challenges, as they arose. There can be many real and perceived roadblocks to dementia inclusive programming, from trained staff, safety, to insurance coverage. However clever and creative leads needs to be to get a program cleared to launch in their organization, the design and offerings of the programs themselves should be **simple**. Programs do not have to be "fancy" or claim to do everything. The paramount aim of any

Key Learnings for Action

- Acknowledge and value the influence of place and past experiences
- Enable people living with dementia to lead
- Embrace and commit to collective action and collaboration
- Invest time in building relationships across organizations
- Think small before thinking big
- Adopt an asset-based approach – work with what is already in place
- When considering program content remember: 'go with what gives you pleasure.' People need to have fun and be motivated to participate
- Include people living with dementia in all stages of program development
- Intergenerational programming is attractive and offers unique benefits
- Parallel opportunities and programs for care partners
- The space in which the program is offered can "make it or break it."
- Root programs in an organization to enhance its ability to be sustained
- Keep program offerings simple, create a sense of belonging, and leave the diagnosis at the door
- Despite all the effort and great rationale in the design a program, be ready to adapt
- Create transition plans when programs no longer fit needs

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

program with and for people living with dementia should be to create a **sense of belonging**. Another critical feature is that programs should balance **"leaving the diagnosis at the door"** with setting positive examples of how to live well with dementia. Gauge what people want and need at the design phase and as the program rolls out, **be ready to adapt to participant needs**. Lastly, in any dementia inclusive program, anticipate that participants may eventually need to **transition** out of the program. Consider what that transition should look like and ensure it is supportive to both the participant and the care partner.



Ideas to Actions Panel

Conclusions & Next Steps

Workshop participants concluded that it would be of great value to have a platform, beyond the workshop, to continue to share stories and experiences of dementia inclusive programs as well as data from program impact and implementation evaluation. These knowledge sources will help break down stigma that exists in community and will help build support at the political and funding levels for future initiatives that promote and enable dementia inclusivity.

The workshop closed with participants sharing ideas and actions that they will pursue in their own work and as part of the Building Capacity Project. Participants reflected on their experiences as well as the inspiring approaches shared in workshop. The asset-based, community-led approach that underpins the Building Capacity Project was viewed as an appropriate and essential way to pursue research and operate programming in community settings. Workshop participants underscored how valuable it was to be able to network with others who have experience with dementia and dementia inclusive programming and how valuable it was to share experiences with program development and implementation processes.

The site and research leads will integrate the workshop learnings and stories to inform the approach and priorities of the Building Capacity Project in the years ahead. These learnings will also inform the approach to research and evaluation within the project.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Background

The Project

The '*Building Capacity for Meaningful Participation by People Living with Dementia*' (or Building Capacity) Project is the first to launch under the Public Health Agency of Canada and a new federal [Dementia Community Investment Strategy](#).

At its core, the Building Capacity Project aims to enable people living with dementia to participate in community life – and to have access to physical and social opportunities. To guide the project forward, the team uses a 'bottom-up,' asset-based community development (ABCD) approach to foster the growth of initiatives² based on community capacity (McKnight & Kretzmann, National Civic Review, v85, no. 4, 1996). An ABCD approach builds on local assets and interests while seeking and engaging community champions, local leaders, service providers, and other key stakeholders in the design, implementation, and adaptation of the initiative. Further, an ABCD approach looks to integrate programming into existing systems and networks. Top-down or predesigned approaches can overlook community context and can neglect important features that propel initiatives to success. As a result, initiatives become harder to implement and sustain.

The project engages two distinct communities: Vancouver's Westside through the Westside Seniors Hub (WSH) Working Group and researchers from University of British Columbia (UBC) as well as Thunder Bay through the Northwest Dementia Working Group (NWDWG) and researchers from Lakehead University. Together they unite under shared project aims:

1. Implement an ABCD approach to create and/or adapt community programs and services that are meaningful and inclusive for people living with dementia.
2. Conduct 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 living with dementia.
3. Disseminate learnings to increase awareness and to support other communities in their efforts to create and/or adapt opportunities for meaningful participation by people living with dementia.

The Workshop

Over the course of two days, the Building Capacity Project research leads and WSH hosts gathered stakeholders and community champions, and advocates from the project's two communities as well as others from the Lower Mainland and Seattle area. The sessions took place at UBC Campus (Cecil Green Park House) as well as various WSH partner organizations on Vancouver's Westside.

Partners from both sites hold important information and insights into how best to design, implement, and evaluate meaningful and appropriate opportunities for people living with dementia in their communities.

The primary aims of the workshop were to share knowledge, spark and connect ideas, and build relationships. When community and research leads have a shared understanding of the issues

²In this report we use the term initiative, innovation, program, and opportunities interchangeably. The terms are used to mean a set of related measures or activities with a particular long-term aim of engaging people living with dementia in community life.

Building Capacity for Meaningful Participation by People Living with Dementia *A Project under the Public Health Agency of Canada's Dementia Investment Strategy*

Workshop Report

and opportunities, they are better positioned to deliver on the project's aims of co-creating meaningful community-based initiatives for people living with dementia and translating their experience for the benefit of other communities. The workshop was also intended to surface some of the design, implementation, and evaluation considerations for both the Westside Vancouver and Thunder Baysites.

Workshop's aims:

- Build relationships and a shared understanding of the issues and opportunities within the Building Capacity Project.
- Highlight project progress, to date
- Share the stories of inspirational initiatives for people living with dementia
- Surface barriers and facilitators to the design and implementation of successful initiatives
- Surface considerations for the evaluation of initiatives
- Identify mechanisms that enable the sustainability of initiatives



Members of the North West Dementia Working Group, West Side Seniors Hub, and Building Community Capacity research team at Jericho Beach.

Workshop Report

Day One – Building Leadership Connections

Tuesday, February 18th

Objectives for the day:

- Building connections between the community and research leads at each site to position the project for effective, collaborative leadership
- Build rapport across sites that will facilitate knowledge sharing and collaborations
- Surface unique and common features between sites
- Identify assets and opportunities embedded in each site
- Surface perspectives and priorities of researchers and community leaders
- Start to build a shared understanding of the issues and opportunities within the Building Capacity Project.

Morning Tour – Highlights

The WSH hosted the morning tour. The aim of the tour was to show the NWDWG some of the sites of the WSH partner organizations as well as the neighbourhoods in which they are situated. By interacting in these spaces, participants had an opportunity to gain a deeper appreciation of what engagement of people living with dementia could look like in the Westside of Vancouver and how this compares to the Thunder Bay area context.

The morning started with a drive-by tour of the Pacific Spirit United Church, A.S.K. Friendship Centre, and Kerrisdale Seniors Centre. Participants had an opportunity to see these sites, learn about their mandates, and hear about their plans for supporting people living with dementia. The next stop was the Kitsilano Neighbourhood House, where WSH partners hosted breakfast and coffee and showcased the space and programs.

Later in the morning, Peter Phillips welcomed workshop participants to Brock House, a community centre for seniors. He provided historical background of the building, an overview of the programs offered, and Brock House's relationship with the City of Vancouver and surrounding community. He shared ideas of integrating dementia as a topic in their men's groups as well as other programs. During lunch, the WSH and NWDWG members mingled and shared experiences with anti-stigma initiatives. Clara Mersereau, a member who lives with dementia, explained the origins of the t-shirt she had printed after being diagnosed, which read "I May Have Alzheimer's But It Does Not Have Me," the meaning it held for her, and its impact on others. She went straight from the doctor's office after her diagnosis to a local t-shirt shop to have it printed. At that moment, she was not going to let the diagnosis define her, her abilities, and how she lived her life.

After lunch Angus McIntyre, a local historian took workshop participants for a walking tour along Jericho Beach and towards Spanish Banks, showcasing the community's natural and historical assets. Angus focused on the various forms that the beach area and Jericho lands have taken since the 1950s, pointing out that the lands as ancestral territory were rich hunting and fishing grounds, used by the Mosequeam, Squamish and Tsleil-Waututh First Nations. The more recent usages included shipyards, landing strips, army bases, the Habitat conference venue, and derelict

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

parkland. The walking tour and Angus's historical overview highlighted the evolution of space use over time, the possibilities of change, and the role of community in designing and defining what community opportunities and assets should look like. For example, Angus spoke of the 1970 plan to convert the Jericho lands into a housing subdivision. The community revolted and won over the planners, developers, and City Council. Inspired by the stories of the past, workshop participants considered how community programming could also look different – more inclusive of people with dementia.

Afternoon Dialogue – Highlights

Roundtable Reflections

Sarah Lusina, the workshop facilitator, convened the group after the tour and asked participants to share 'top of mind reflections' in a roundtable dialogue. A common, enthusiastic comment: flowers in February!

Beyond the favourable weather for touring WSH sites, it was apparent to both the WSH and NWDWG participants that there are many differences between their communities. Noted differences included built environment and community design, transit options, climate, demographic diversity, service provider offerings and spaces, among other features.

One workshop participant and a Brock House volunteer commented on the beauty of the building but also on its "unfriendly" design for people living with dementia. There are many small, rooms across three floors, with long, complicated names that make them hard to remember. This person also noted that making the space more friendly for people with dementia would be a consideration going forward. Another workshop participant commented on the current, limited intergenerational programs in Thunder Bay area compared to what they have observed in WSH organizations.

Participants agreed that there is a strong connection between community assets, the role of place and neighbourhood, and community development. Some from the NWDWG stated that they feel people are less connected to their community and neighbourhood in Thunder Bay compared to Vancouver. For example, older adults in Thunder Bay tend to drive instead of using transit or walking. The group pondered the implications these different levels of community connectedness on the aims of the Building Capacity Project. Community design and people's habits and behaviours were seen as having significant implications on participation in any Building Capacity Project initiative or innovation.

Participants also noted the commonalities between communities. There is a rise on need for community-based programming for people living with dementia and food is a key motivator for participation. A shared meal or refreshments provide people with the opportunity to converse, be nourished, and socialize. Gathering around food is thought to be the key mechanism of success for Dementia cafés.

Workshop participants also agreed that Clara's t-shirt was an impactful and engaging way to break stigma and normalize the dementia experience. Boldly claiming her Alzheimer's diagnosis and that she is not defined by it acknowledges the importance of retaining a strong focus on personhood in the dementia journey. "The more we see people living with dementia out in the community, the more we can combat stigma and the isolation and loneliness that comes along with it," stated one community-based programmer. When reflecting on the event, the researchers

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

noted how Clara's shirt exemplified the power of personal contact in combating stigma, especially when people see examples of people who are living well with dementia in the community.

Showcasing Communities – Structures & Settings

To support this session and the community profile presentations, Sarah provided a brief overview of a few key concepts that underpin the work of the Building Capacity Project.

Socio-ecological frameworks

When considering community initiatives that are inclusive of people living with dementia, we need to take a socio-ecological framework, which acknowledges the role of social and environmental factors that influence health and wellbeing. This framework can assist in providing a more holistic perspective of the factors that affect specific health behaviors and opportunities.



Sarah also spoke of the concept of the 'four-legged stool of society.' In a Kettering Foundation report,³ John McKnight, a renowned community developer and thought leader advances the idea that society is comprised of four "legs": government, private, not-for-profit, and civic associations (see the report for a more detailed definition of each at their common interactions). Society is unbalanced and dysfunctional when any one of these legs is unstable, too short, or too weak. Relevant to the work of the Building Capacity Project, this concept points to the need

for all "legs" to be strong and to be part of initiative development and sustainability. Each have an important role. The initiatives will face impact and sustainability challenges if government, private, not-for-profit, and civic associations are not appropriately engaged. Further, the "leg" that is often missing is that of civic associations, whether formal or informal. The NWDWG is a good example of a civic organization that brings critical perspectives to dementia inclusive initiatives in their community. Their involvement and leadership make these initiatives more relevant and impactful than they would have been without the participation of the NWDWG.

Highlights from the North West Dementia Working Group (NWDWG), Thunder Bay
The NWDWG presented on how they have organized and what they have accomplished, to date. Elaine Wiersma and each NWDWG member took turns contributing. This presentation style illustrated their deep commitment to collaboration, the importance of including the voices of people living with dementia, and shared ownership of the work.

The NWDWG is not a formal organization and it identifies as an independent, grassroots, civic group. Due to their historic collaborations the NWDWG is often thought to be funded by Ontario's Local Health Integration Networks or facilitated by the Alzheimer Society - however, neither are true. It is comprised of people living with dementia and care partners. Elaine and her team at Lakehead University's Centre for Research on Aging and Health (CERAH) support the group by coordinating meetings, as well as providing logistical support and refreshments. The relationship

³ Reference: www.kettering.org/sites/default/files/product-downloads/The-Four-Legged-Stool.pdf

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

with the team at the university has enabled the NWDWG to be a part of many research and outreach initiatives and the bidirectional exchange of knowledge and information has been mutually beneficial in advancing one another's work.

The galvanizing mission of the NWDWG is to be a voice for people living with dementia. They want to ensure that people living with dementia are treated with respect, dignity, and afforded human rights. Presenters underscored that they are not a support group – *the aim is action and to get things done!* The presenters note that because NWDWG is an independent group, they control the mandate, mission, and vision.

"I have Alzheimer's
it doesn't have me"
– Clara Mersereau,
Advocate living with
dementia



Members of the North West Dementia Working Group at the Toronto Pearson International Airport.

Despite its informal structure, they have had significant success in supporting people living with dementia in their community, influencing government priorities, and educating the public and health workers. For example, in 2015, the Parliamentary Secretary to Ontario's Minister of Health sought the NWDWG's contribution to the Ontario Dementia Strategy. The group has developed presentations and training material to educate the general public about dementia, to address the stigma associated with dementia, as well as recommended acceptable language, descriptors, and communication approaches. The group has also presented to health workers, including nursing students, personal support workers (PSW; also known as care-aides) and PSW trainees. Their most notable, recent effort was a conference they organized in September 2019: "Living

Well with Dementia – Creating Dialogues of Hope." The idea came from a NWDWG member living with dementia who wanted to bring people from across the mostly rural region together to share stories, learn from each other, and create hope in the connections. A New Horizons grant provided the funds to support the participation of more than 100 people (35 living with dementia) spanning 700 + kilometers.

"I think some people think it's a stigma to have dementia—I never thought that. It is important to change their mind. It is not a stigma. It is a condition. You can challenge it and move forward. You don't need to go into the shadows ..." – NWDWG member

Highlights from the Westside Seniors Hub (WSH) Working Group, Vancouver

The WSH Working Group also provided a collaborative presentation of how they have organized and what they have accomplished, to date. The WSH Working Group is made up of Hub partner organizations, a senior-led Hub Council, and issue-based, action-oriented committees. The WSH mission is to build a more responsive and resilient seniors' community on the Westside of Vancouver through the power of collective action.

The Hub has ~20 partner organizations operating in the catchment area bounded by English Bay (north), Ontario Street (east), Fraser River (south), and inclusive of the University Endowment Lands (west). Partner organizations are non-profit organizations, faith-based organizations,

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

government agencies, or professional associations that serve seniors. All partner organizations have an interest in collaborating with others to support seniors in their community.

WSH hosts partners meetings every four months. Within these meetings partners provide updates on programs, resources, and look for ways to collaborate and share with each other. An example of a successful, shared venture was "Vancouver Walk and Be Seen 2017-2018." The impetus for this was growing concern that many seniors were unsafe walking on the streets as lighting was an issue. A number of Hub partner organizations came together to seek funding through New Horizons and Vancouver Coastal Health. After securing funding they collaboratively designed an impactful innovation for pedestrians and drivers, focussing on safety during Vancouver's dark winter months. Sabina Harpe, a WSH Council member handed out the fluorescent, flashing yellow band they developed to the meeting participants.

Despite the strong network of organizations, the presenters noted a shortcoming in their structure is that they do not yet have representation and leadership from people living with dementia. They are actively seeking new ways to reach out to people living with dementia and could use some support and guidance on how best to do this.

As the community presentations concluded, Elaine provided a statement that illustrated the value to the community presentations. "Each community is like puzzle piece," she said. "They each hold important information about what it takes to create inclusive communities for people living with dementia. One community is taking an 'inside out' approach, starting with their experience of living with dementia and working to influence external organizations. The other is working from the 'outside in' where organizations are linked and positioned to be inclusive of people living with dementia. By learning from each other's experiences, we put the two pieces of the puzzle together and we will make a big difference."

Collaborating with Researchers

Elaine and Alison reviewed the global aims of the Building Capacity Project and some of the benefits of collaborating with researchers. Though the project will include some research and evaluation components, more than anything it will focus on making meaningful, sustainable change in communities that benefit people living with dementia – and learning from that change.

The primary activity of research will be to observe and describe the process of program development and the implementation of these programs. By capturing this process and the impact the initiatives have on participants and the pilot communities, the Building Capacity Project will be positioned to accelerate change in other communities as they strive to create more inclusive opportunities for people living with dementia.

Embracing a 'participatory action' and asset-based community development approach, where community stakeholders and researchers co-develop research questions, set priorities, and develop methods, Elaine and Alison see themselves as guides and synthesizers. They both come with decades of experience with dementia in clinical and research roles. They are both passionate about creating more inclusive communities and look forward to using the evidence generated in this project to catalyze policy and practice changes across all levels government and society to create more inclusive opportunities for people living with dementia. Elaine and Alison are both thrilled to be part of this collaborative group that forms the Building Capacity Project.

Workshop Report

Day Two – Engaging Community Partners & Sparking Inspiration

Wednesday, February 19th, 2020

Objectives for the day:

- Spark inspiration from various community-based projects and create connections between people and ideas.
- Surface the value of people living with dementia as active and connected in their communities.
- Identify features of communities that promote success and features that create challenges. Consider current and historic engagement with persons living with dementia and emergent opportunities that could be leveraged.
- Spark ideas for programs/program features for people living with dementia in Westside Vancouver and Thunder Bay, including program components, implementation ideas, evaluation needs, and essential collaborations and/or partnerships.
- Surface ideas on key outcomes that programs within the project sites should target and consider how these might be captured.

Opening Welcome

Thelma and Art Stogan, local Musqueam Elders, welcomed the 'Building Capacity' workshop to their territory. Thelma underscored the importance of openness and storytelling – and how this value will support the work within the Building Capacity Project. She also underscored the importance of valuing and honouring our older generations and histories – critical tenets of the Building Capacity Project. Based on their personal experiences, they shared a story about a sibling who is worried about developing dementia and the ways their sibling strived to maintain her own health and wellbeing.

Alison Phinney and Elaine Wiersma, the research co-leads for the Building Capacity Project, provided a brief overview of the Public Health Agency of Canada (PHAC) Dementia Investment Strategy and the roadmap of the project for the upcoming years.

Sarah Lusina, workshop facilitator, integrated the themes and ideas from the first day of the workshop in order to guide the agenda forward. She noted that much of day 1's activities focused on histories and previous experiences – both at the organizational and individual levels. She encouraged all workshop participants to consider their own histories how that influences their perspectives and assumptions entering into the Building Capacity Project. Sarah highlighted the insights shared by Thelma on the importance of openness and welcoming of new ideas and new people. As Thelma noted, telling stories and sharing experiences will position communities for creating durable change. As Alison stated on day 1, coming together as two unique communities and sharing experiences provided more pieces to the puzzle on the shared goal of making communities more inclusive for people living with dementia.

Workshop Report

Keynote – Social Engagement & Dementia: The Lived Experience

Myrna Norman was diagnosed with frontal lobe dementia eight years ago. Her doctor simply stated: "Go home and get your affairs in order – you likely have 5 to 10 years. Any questions?" Myrna spent the next couple of years doing just that, including a significant move from her home to a "small place with no stairs." She grieved, she became apathetic, she managed her symptoms, including hallucinations, emotional outbursts, and "feeling out of control". In those years she never imagined that she would become an outspoken advocate for people living with dementia.



Myrna Norman during her Keynote Presentation

Over time, her perspective shifted and she realized that she could do more by helping than by fearing what was to come. Myrna is known as a fierce advocate for people living with dementia and holds advisory and advocacy roles on the Dementia Alliance International, Dementia Advocacy Canada, and Alzheimer's Society of BC. She points out that few people who are diagnosed with dementia are assertive enough to advocate for themselves and for therapies that will help them remain independent. Like she did, they struggle with overwhelmed with "anticipatory grief."

For Myrna, a few factors enabled her to move from grief to action. When hospitalized for a short time, she recalls the sound of her door being locked as the care staff exited. That 'click' sound stuck with her – she knew things were different, and she knew that this kind of care was not what she needed. She also found that the language and terminology used to describe her

diagnosis was off-putting. She craved terms that were fact-based and did not point to specific limitations inevitable with progression in the disease – like "memory loss." Myrna advanced that language is important and that people living with dementia have to influence and own that language.

Connections with supportive people also enabled her to find her advocacy voice. Staff and volunteers at the Alzheimer's Society believed in her abilities and the value of her skills and perspectives – and they encouraged her to "speak up." She also was able to educate herself and others on dementia facts and in doing so she could break down stigma and misconceptions. Another pivotal moment for Myrna was the invitation to participate in Momentia events focused on self-advocacy training for people living with dementia.

Myrna serves as a Purple Angel Ambassador, positioned to advocate and educate on dementia. She believes that it takes the work of each individual in a community to make real

change and so she targets schools, clinics, churches, and community groups for her outreach work. There is a need for more people living with dementia to do advocacy work so that the community becomes more familiar with positive examples of what dementia really "looks" like. Myrna encourages those living with dementia to be proactive and get involved if they feel that it will help them cope, process, and keep engaged in life.

Myrna endorses a free web-based course called "Getting to Know Dementia" offered by Tasmania University www.utas.edu.au/wicking/understanding-dementia

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Writing is Myrna's creative outlet. Her writing projects have also supported her educating and advocacy efforts. She produced a poetry and prose book and regularly takes assignments for a local paper.

By sharing her experiences, Myrna provided deep insight into what it means to live with dementia and to have so few opportunities to connect in community. Myrna's story demonstrates that people living with dementia must be supported so that they can remain as active, contributors to society and their own futures. "People living with dementia need positive and supportive care partners, friends, and family," Myrna stated. It is important that these people educate themselves and focus on the skills and abilities that remain within their loved one.

Pearls of wisdom from Myrna's keynote address

- "Humour is really important."
- Do what makes you feel good. Cooking and baking, a previous passion of Myrna's became tedious and frustrating. "Stop if it is a struggle and move on to something that brings you joy."
- She has concerns regarding medical assessment forms – how can we make sense of our scores if we do not have a baseline to compare it to?
- People with dementia are constantly discouraged about their capabilities and worth from the moment they receive diagnosis. As a result, they may not feel they are able to get involved in advocacy.
- Empathy is important, so try to learn more about what the experience is like. Access to your senses and integrating sensory cues is challenging. It is like putting a tiny pill in a small container while blindfolded and with bulky gloves on.

Panel – Perspectives on "The Lived Experience"

A diverse panel shared their perspectives on the themes and issues that surfaced in Myrna's keynote presentation. Panelists shared the statement voiced by Neil Horne: "Myrna is a very special lady... not everyone can do what she does." The panel's unifying perspective was that it was important for people living with dementia to be supported to move beyond their grief and "prescribed disengagement" and towards advocacy and active participation in community life.

Neil Horne, Care partner for his wife, Vancouver

Drawing on his experience as a care partner for his wife who was diagnosed with dementia, Neil reminded us that "not all of people living with dementia are going to be as positive and outgoing as Myrna. There are as many personalities and differences in dementia as there are in the general population." Neil also reminded workshop participants that the abilities and interests of people living with dementia change over time and it is important to account for this in any community initiative. He alluded to the idea that programs should adapt; be flexible to the anticipated and unanticipated changes and needs of people living with dementia.

Neil noted the value of and need for a "train the advocate" type program where people living with dementia could be supported to advocate for themselves and others in ways that fit their preferences and personalities. Based on his personal experience, he underscored that service providers should engage people living with dementia in a way that reflected a genuine interest in forming a relationship – a friendship. People living with dementia want to belong and feel welcomed, just like everyone else. Starting from a

"Dementia is terminal...but we get on with it"
– Neil Horne, Care Partner

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

place of friendship provides that feeling of welcome, acceptance, and inclusion. He wondered if this could form a tenet of dementia inclusive training for organizations and service providers. When communities and organizations are caring and inclusive of people living with dementia, it projects a message that they are still a valued part of community.

Since his wife was diagnosed nearly a decade ago, Neil noted that much has changed – and for the better. In the early years of her diagnosis, there were few community programs or care options. It was a struggle for both of them. As a care partner, he needed to get away and forget about reality for a while just as she needed a change of scenery and an opportunity to engage with others. Neil is heartened to see the opportunities that abound now. Though much still needs to be done, progress is well underway.

Clara Mersereau, advocate living with dementia, Thunder Bay

As a person living with dementia, Clara advocates for the importance of positive opportunities and the opportunity to stay positive. For her, this means being social. She attends a day program run by the Victoria Order of Nurses as well as Thunder Bay's Dementia Café and other opportunities to interact and participate in community life – like spending time with her grandchildren. These outings give her the purpose and social contact that keeps her positive and living well with dementia. "Keep yourself social – keep your mind off of it," she said. "That is key." As someone who was always quite shy, she feels she has found her purpose in her diagnosis – to make community life better for others living with dementia. "[The diagnosis] has given me a lot of self-confidence. It's helped me find my voice."

Kara Turner, Executive Director, A.S.K. (Arbutus, Shaughnessy, Kerrisdale) Friendship Centre, Vancouver

Kara noted over 80% of people at ASK have dementia and that her previous position at ASBC has helped her in her current work. "Our clients are not able to do what Myrna does so we provide a place of purpose and belonging based on people's abilities," Kara said. Not everyone can play the important role of advocate, so ASK tries to fill that role. As an Adult Day Centre focusing on the wellbeing of seniors and their care partners, ASK is galvanized by providing opportunities to make new friends and have fun doing therapeutic activities with the support of a caring team of trained staff members. She said they try to create opportunities so people can experience success, as opposed to being frustrated about not being able to accomplish something. At its core, they are a friendship centre: a place where people can feel like they belong and can be together. "That's all anyone wants," Kara noted. "To be part of a group and community and to belong."

Themes from the Panel

- Engage
- Educate
- Advocate
- Include
- Integrate
- Fun
- Laughter, humour

Alison Phinney, Building Capacity Project Co-lead, University of British Columbia

Alison shared her experience as a young nurse and her first interactions with the medical system and people living with dementia. The medical system seem so closed to learning more about dementia – but she was genuinely curious, sure that there was more to the experience of dementia than the medical system acknowledged. This curiosity led to a career in research. When she proposed a PhD dissertation that involved listening to what people with dementia had to say, she experienced skepticism from the research colleagues. Her astute observations, tenacity, and

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

genuine curiosity has led to a rewarding journey researching and teaching about the dementia experience.

To her projects, Alison brings to the skills of deep listening. "I like to listen, but that is not my privilege anymore." She talked about supporting people with dementia to speak for themselves, noting that it takes a lot of courage to speak out and advocate. She also talked about how the Building Capacity Project presents an opportunity to move beyond listening and to effect positive change. She also spoke of the importance of working with good people with shared values. The shared values of all the committed collaborators in attendance at the workshop will form the foundation upon which additional stakeholders can be engaged and included in this call to action. Alison is inspired and committed to engaging decision makers and stakeholders who can make things happen, and who can support positive change for people living with dementia.

Elaine Wiersma, Building Capacity Project Co-lead, Lakehead University

As someone who researches dementia experiences and supports the NWDWG, Elaine highlighted the importance of getting to know people as people and of letting them guide how best to interact with their diagnosis. "We need to listen...we also need to ask. If we don't ask we won't always have the opportunity to listen." This includes asking about the terminology and language that they prefer when referencing their diagnosis. It also includes asking people what they need and how we can help to make things better, or different. Like Alison, Elaine talked about listening as the springboard to action and that she is deeply committed to engaging stakeholders across all levels to build the momentum needed to spur sustained, meaningful changes for more dementia inclusivity in community.

Building Community Capacity for Social Citizenship: Momentia

Marigrace Becker is the Program Manager, Community Education & Impact at the University of Washington's Memory & Brain Wellness Centre. Marigrace wowed the workshop participants with an energetic presentation about an initiative she has helped champion: Momentia. Momentia is a grassroots movement that fosters more inclusive communities and opportunities for people living with dementia. Momentia is led by people living with dementia and their care partners alongside a variety of community organizations such as community centres, seniors centres, libraries, theatres, museums and more. Momentia aims to increase awareness of people living with dementia in the community and to highlight that they are deserving of accessible, equitable opportunities to engage in community, like anyone else.

Momentia formed through convergence of multiple existing groups, all motivated to enable more positive opportunities for people living with dementia in community. These groups initially operated in parallel to one another but eventually, and organically, they started to connect and collaborate. As a coalition, organization representatives all agreed that they had to start somewhere. To create a foundation for shared work, they started small, developed relationships with one another and identified shared interests.

Marigrace underscored that programming is most successful and rewarding for people living with

Momentia was inspired by a comment made by a community member living with dementia: **"Alzheimer's is not a disease, it's an adventure."** This statement drastically changed the way Momentia founders thought about dementia experience and it inspired how they were going to pursue more dementia inclusive opportunities in community.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

dementia when it is designed around being present in the moment and when it focuses on abilities. Programming must also acknowledge the fact that no two people living with dementia are the same. Their needs vary and change over time. As a result, programs and approaches need to be dynamic and fluid to remain inclusive, supportive, and effective. Some great examples include: garden discovery walks in nature; arts discussions and art-making; volunteer tasks that are straight forward and enable the participant to enjoy the feeling of giving back (i.e. food sorting at a food bank); collaborative music-making and listening; Alzheimer's/memory cafés – social gatherings in a stigma-free space, enjoying each other's company). Programs associated with Momentia are evaluated from time to time but these investigations are pursued independently from Momentia.

To close her dynamic presentation, Marigrace led workshop participants through a call and response rap song about Momentia and reducing stigma. Workshop participants had fun breaking down stigma and signing along with Marigrace!

How to bring the successes of Momentia to your community

1. Follow the lead of persons living with dementia. This is a core principle of Momentia.

Persons living with dementia are the authorities of what it means for them and what meaningful engagement looks like. Connect with people living with dementia in your community and ask: what brings you joy, what is a gift that you have to give, what is a place in your community that you love?

2. Work with others. Another core principle of Momentia is that we are better together. You will have more success if you do not try to do it on your own. We all bring different skills and interests, passions, and resources. They all need to be at the table. Continually consider who else could join you in your efforts. Listen and be collaborative. Bring together organizations and enable/empower them to host community forums. Empower people to create bold dementia-friendly ideas using the assets and unique backgrounds of every person involved. When working with others, recognize their strengths

3. Incorporate neighbourhood assets. Work with what already exists in the community and embrace its uniqueness – parks, museums, cafés, theatres, galleries, community centres, and more. Think through creative ways to use these spaces.

4. Go where the energy is – look for open doors. Pay attention to and follow up with those who says "yes." Where are the open doors? If you find yourself frustrated or coming up against roadblocks, shift in a direction where you sense more openness and enthusiasm. If you are aiming to start an Alzheimer's Café but a coffee shop declines, keep looking. If you continue to hear 'no,' go back to Tip # 1 and brainstorm another idea. The best option is when everything just "clicks" and everyone is excited to be a part of it.

5. Keep it simple. Start in a safe, comfortable community setting that enables people to attend and that is not intimidating. Make sure that there is time to connect with others. The program offerings do not have to be flashy. Consider a one-time event, a pilot program, or bringing something to your community that has worked elsewhere. You do not need to re-invent the wheel. Hosting a Dementia Café can be a good place to start.

For more information and ideas, see: www.momentiaSeattle.org

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Panel – Turning Ideas into Action & Success

From arts-based to fitness, social, and educational approaches, this panel showcased how an innovative idea grew into actions and benefit people living with dementia.

Clara Mersereau, North West Dementia Working Group
Elaine Wiersma, North West Dementia Working Group & Lakehead University
Dementia Café volunteers, Thunder Bay

Elaine and Clara spoke of their successful Dementia Café. They warned workshop participants that initiatives are not always successful from the “get go.” Their first attempt was a “flop.” It was situated at a library, the only place available at the time. It was a small space and awkward to be social in. Parking was also a challenge. There were very few parking spaces in a small lot. People living with dementia attended with their care partners, so finding a venue with convenient parking is critical for participation. In this first café attempt, Elaine and the NWDWG made the assumption that people who attended were in need of support information, so the Dementia Café focused on providing health and social service resources. However, no one seemed interested on these materials. Upon entry into the café, they also asked about people’s diagnosis in an effort to monitor program reach and participation. These offerings and information gathering were off-putting and led to low attendance.

Programs do not have to be “fancy” or claim to do everything. Paramount in any program should be the aim of creating a sense of belonging.



Elaine Wiersma and Clara Mersereau

Sure that the need for dementia inclusive social opportunities was real, Elaine and the NWDWG decided to take a different approach. They decided to relocate the Dementia Café to a newly renovated and spacious church hall with bright stain glass windows, a full service café, and ample parking. The Dementia Café programming also changed. It focuses on social connections, delicious food, and even musical performances, on occasion. It is ‘a place to belong.’ The Dementia Café operates on an “open door” policy – no registration or diagnoses are requested.

This ‘take two’ of the Dementia Café now attracts 30-60 people each weekend and even has a volunteering wait list. Even though there have been many requests from members of the community at large, volunteer selection prioritizes those living with dementia, care partners, and then others who wish to commit their time.

New Dementians Choir & Café
Dorothy LeClair, Program Manager, Seniors Outreach Society & Jennyfer Hatch, Music Therapist
Burnaby Community Services, Burnaby BC
www.bsoss.org

A few years ago, Dorothy established a Dementia Café at the Seniors Outreach Society. The choir idea emerged from conversations at the café. Dorothy underscored that the success of the Dementia Café was key in their ability to launch a choir. Through the café, they established a “safe

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

space" where people had a sense of belonging and they had a good understanding of what people living with dementia in their community wanted. From here, they could try something new.

Café participants were drawn to the recorded music that Dorothy provided and they indicated that they wanted an opportunity to sing. As a self-proclaimed "bad singer" and committed to the needs of the people participating in the Dementia Café, Dorothy sought someone with musical training and who would be skilled at meeting the needs of people living with dementia. Dorothy reached out to her network first. Through a series of emails, phone calls, and recommendations, she was connected with Jennyfer, a music therapist. Jennyfer was keen and she now leads the music offerings at the Dementia Café including a music 'dessert' menu – a list of songs for people to sing together as a way of closing the cafe gathering.

Having witnessed the success of the music offerings at the Dementia Café, Jennyfer and Dorothy wanted to create something more intentionally focused on music. They applied to a number of grants to secure funds for a dementia inclusive choir and they were successful.

The New Dementians Choir welcomes all comers – and that is part of its strength. No musical training (or talent) is required – just an interest in singing! Based on the requirements of the funder, programming must be intergenerational and multi-ethnic. As a result, agreement on repertoire has proved challenging. Participants vary in genre type preferences and ethnic and language backgrounds. Jennyfer has risen to the challenge and has been able to find musical selections that have something for everyone and she primarily draws on suggestions from participants of the Dementia Café and choir.

The intergenerational feature of their choir provided a unique dimension, however, operationally it is hard to find and entice youth to participate. They have placed the choir on Saturday mornings at 10 am to avoid school day conflicts, though youth have yet to engage. Meeting the needs of two unique groups within the same program proves challenging.

The choir has become quite popular and they now face space limitations. With 30 members currently participating, including people living with dementia and their care partners, they are at the upper limit of what the space can tolerate. Finding a low cost or free space that is large and acoustically sound is a challenge. Aside from space, ongoing funding will also determine their ability to operate. Motivated and spurred by her vision for the choir, Dorothy has already started compiling a list of potential, philanthropic donors.

To get innovations and new programs off the ground, Dorothy spoke about the importance of calling and making personal connections with potential collaborators. "People can ignore and delete emails more easily than phone calls." It was clear that Dorothy's commitment and vision enabled the development and launch of choir. The choir is in its sixth month of operation, but has been a huge success so as it meets a real need and interest of people living with dementia.

Raising the Curtain

Bruce Devereux, Recreation & Volunteer Manager, Good Samaritan Society, Gibsons, BC
deercrossingtheheartfarm.org/programs/the-imagination-network/

Bruce leads "Raising the Curtain," a community-based participatory research program that uses creative arts to tell and talk about lived experience of dementia, while evaluating and learning from the experience of program providers and participants – people living with dementia. The program originated partly out Bruce's work at the Good Samaritan Society and his desire to challenge community perceptions of what dementia was all about by using insights available through the creative arts.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Bruce networked with artists and community organizations and the idea of "Raising the Curtain" began to take shape. Around the same time, they met Colleen Reid, a Recreational Therapist with a research background and they developed a proposal for an action research project. By staking support from a number of funders they were able to cover the costs of programs. The British Columbian Council for the Arts, the Government of Canada, and the Vancouver Foundation funded the research. The initial goal of the program and the research arm was to design and evaluate the impact of a "new model of care" but the project has taken a nuanced shift of focus and now focuses on a "new model of a living community." Bruce emphasizes the need for innovation to be grounded in a strong vision.

With a few years of experience now, the program has honed its delivery model. They provide weekly workshops for 8-9 months per year and participants generate themes to be explored in each workshop. For example, to explore the theme of 'stigma,' participants decided to create a sculpture of a giant elephant to emulate the giant "elephant in the room" that follows people living with dementia. To explore the theme of 'managing the unknown,' participants created a shadow-puppet show to share a story that reflected this common struggle. Program participants are working towards a public performance in July 2020.

Part of what has created some sustainability for the project is its association with the research team. Through the research and evaluation component, the creative venture has obtained funding, is guided by the learnings of the evaluation, and gains credibility because the evaluation is able to demonstrate impact. Both the research and creative documentation of the program are complimentary and contribute insights in how to transfer knowledge to future projects aiming to be inclusive of people living with dementia.

As is the case in most rural and remote communities, transportation is the main challenge they face when it comes to program participation. Getting people to and from the workshops can be tough to coordinate and fund. Many funders set limits on the amount of fund that can be used to support and coordinate transportation – and that can dictate what participation looks like. Further, Bruce noted that the 'small town' vibe in Gibsons and the Sunshine Coast areas mean that many people are reluctant to identify as living with dementia. "Everyone knows each other and it's hard to find people who are outspoken about having dementia," he says. Stigma runs strong in small communities. The experience of "Raising the Curtain," however, also shows that in tightly knit communities, people can come together and challenge stigma.

Paul's Club – a social and recreational adult day program, Vancouver

Nita Levy, Founder

Genevieve Ling, Recreation Therapist

<https://paulsclub.weebly.com/about-us.html>

Nita shared the story of how Paul's Club came to be. Her and her husband, Michael Levy were inspired by the personal journey of Michael's brother, Paul, a healthy man diagnosed with Alzheimer's in his 50s. Paul lived in the United Kingdom while Nita and Michael live in Vancouver. As Paul progressed with his diagnosis, navigating programs and services was tricky not only because of the geographical distance between them, but also the circumstance of being so young.

In their experience, no program offered in the community or health setting met Paul's needs. In the community space, it was hard for Paul to engage and feel included in typical programs offered for all comers. In the health space, adult day programs were comprised of people much older than Paul with significantly higher support needs than Paul. It seemed he did not belong.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Committed to ensuring others did not have to feel that same miss-fit, Nita and Michael set out to create a social and recreational day program for people living with young onset dementia and that caters to the specific needs and interests of people diagnosed before the age of 65. Paul's Club opened in 2012 and is currently the only program of its kind operating in Vancouver. The club is open three days a week, from 10 am – 4 pm, and operates 50 weeks a year. They mostly support those with Alzheimer's, but are inclusive of other forms of dementia and people from outside of Vancouver.

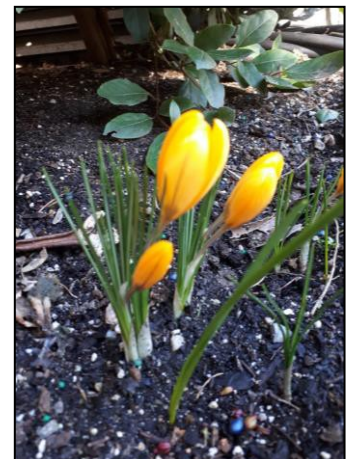
They had to get creative in finding a way to fund and operate the program. Nita was able to draw on her former career as a nurse to explore whether health system integration was possible. "Nobody knew what to do with us or wanted to accommodate us," she said. There were many barriers in securing a location. Frustratingly, the health authority was not in a position to offer this kind of programming or to provide space. According to zoning and licensing regulations, an adult day program needed a certain amount of accessible outdoor space, as well as accessible parking spaces. Nita and Michael wanted to ensure that the program was affordable, so a market rental would not work. Realizing that hotels met the zoning and licensing requirements, they pitched the idea to the Hampton Inn in downtown Vancouver – and in a stroke of luck, they agreed. To support some of the space and material costs of the program, Nita and Michael have run many fundraisers and have secured a sponsorship from VanCity Bank.

At its core, Nita stated that the club has a warm, welcoming atmosphere and provides a physically and emotionally safe environment. The focus is on being social and active; there is little or no mention of why people are enrolled in the program. "Diagnosis left at the door," Nita said, "and this gives people comfort." As a result, participants can just be – and not be defined by their condition.

Club activities are designed to be fun and engaging. Typically, they start the day with a snack – tea, coffee, and pastries, then take on a game or creative activity like dancing. Lunch is provided at the restaurant next door to the hotel. Participants provided a picture menu and they can select a meal before they arrive at the restaurant to avoid the paralyzing experience of having to make choices in a new environment and on the spot. After lunch, participants can read the paper or just sit relax before heading out for a walk -- and they always end their walks with ice cream!

Of course, it is critical that the programming be appropriate and safe. Chelsea Redburn is a recreation therapist and oversees the design and provision of Paul's Club activities. As Chelsea is on maternity leave, Genevieve Ling has stepped in. The recreation therapists are trained to guide activities for all people, including those with special needs. They are skilled at normalizing interactions, keeping people moving safely, and communicating with people living with dementia.

One unique challenge that Paul's Club has faced is that they are perceived to be *exclusive*. Nita noted that it is quite the contrary – they are and always strive to be inclusive. They never deny someone's participation due to financial constraints. Fundraising, sponsorships, and user fees cover the program costs but user fees can be determined on a sliding scale and waived, if needed. Transportation is another challenge. Nita manages all the transportation logistics for participants, including HandyDart scheduling. They are also challenged with getting the word out that they exist. The UBC Alzheimer's clinic now regularly refers people and Nita does as much outreach as possible.



Flower blooms at the Cecil Green Park House on UBC campus

Building Capacity for Meaningful Participation by People Living with Dementia A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Mary Jane Knecht – Manager, Creative Aging Programs, Frye Art Museum

https://fryemuseum.org/creative_aging/

For over 10 years, the Frye Art Museum has provided programs for people living with dementia and their care partners. Mary Jane initiated this programming and continues to lead it. Over this time, she has learned a great deal about what works and what does not. "I no longer ask 'what stage is your loved one at?'" she said. "I now ask 'would your loved one enjoy this experience?'" It is important to account for disease stage to appropriately design and support people in programming, but leading with their interest is more inclusive and respectful.

New York City's Museum of Modern Art (MoMA) and a special book launch inspired Mary Jane to explore dementia inclusive programming at the Frye Museum. MoMA was reinventing how they used their arts spaces for public engagement and social opportunities and were offering dedicated programs for people living with dementia (www.moma.org/visit/accessibility/meetme). Around the same time Mary Jane learned of MoMA's work, the Frye Museum hosted a book launch for *Beyond Forgetting*, a compilation of poetry and short prose by writers' whose lives have been touched by Alzheimer's Disease. The book launch drew a large crowd from all over the city, and based on the level of interest at the book event, Mary Jane knew that the time was right for the Frye Museum to offer dementia inclusive programming.

Inspirational book:
Beyond Forgetting – Poetry & Prose about Alzheimer's Disease, edited by Holly Hughes.
www.beyondforgettingbook.com



Turning Ideas into Action & Success Panel

Mary Jane explained the diverse neighbourhood in which the Frye Museum is situated. Many hospitals, schools, archdiocese, and mixed income groups are the museum's neighbours. To be relevant to their surrounding community, the museum's education department has committed to providing accessible, inclusive programs across ages, socio-economic situations, and abilities. This track record of being relevant and flexible has contributed to their approach and successes with dementia inclusive programming.

An intentional and unique feature in museum's dementia inclusive programming is that it features separate and dedicated opportunities for care partners.

"Shared respite is really important," Mary Jane said. "Both people need a change of scenery and a break from their routine." Another key feature is that programming is accessible for people who do not necessarily know anything about art, art history, and artistic techniques. "There is no need to memorize dates or characteristics of specific periods. Programming focuses more on people's reaction and immediate ideas on the pieces they interact with."

Programming in a safe, open environment is also a special and unique feature that the Frye can offer. There is space to move around, take a break, and interact in different ways. Despite their efforts to be inclusive and accommodating, eventually the diseases progress and people are unable to continue coming to the museum. This becomes difficult for care partners and the people living with dementia. Relationships and routines are fractured; an enriching asset that was part of their lives is no longer. From this observation, the Bridging the Gap program formed. Here, volunteers go to the residences of people living with dementia and provide art experiences as an extension of what they experienced in the museum-based program. Many of the volunteers are young people developing their art-based work portfolios – and in turn, they are provided with the opportunity to learn more about dementia and social citizenship.

Workshop Report

"Making the Pitch" – Promoting dementia-friendly initiatives

Marigrace shared the process Momentia uses to engage community organizations, such as seniors centres, municipal parks and recreation departments, YMCA's, and other groups to create and implement dementia-friendly initiatives in Seattle. She reviewed the five key steps that have opened doors and brought together unlikely allies. They are summarized below. Refer to Marigrace's handout in the workshop package for a more detailed description.

1. Do your homework

- Research the organization online and through people in your network.
- Consider the mission statement and articulate how a dementia friendly initiative aligns. What makes them tick? What motivates them? What are their values? What are they trying to accomplish? What kind of programming do they already offer?"
- Draw connections to similar organizations that are already undertaking dementia inclusive programming: perhaps that organization could act as a mentor.

2. Schedule a meeting

- Use the phone, not email. Request a time to meet. The goal is to get an initial "yes."
- Briefly explain who you are, what you would like to talk about, a note on how it aligns with what they are already doing, and ask for a good time to meet.
- An in-person meeting is ideal.

3. Prepare for the meeting

- Review your research. "Get their mission statement in your head."
- Put yourself in the mindset of that organization — "know what language they speak and what they care about."
- Sometimes statistics are compelling, sometimes anecdotal stories are better. Be prepared with both.
- Write out a short script to help you stay on track.

4. Meet and make the "pitch"

- If you are not someone living with dementia, consider including someone who is.
- Assume support — go in with confidence. Position the pitch not as "asking" but more as "providing an opportunity."
- Do not use the word "if." Instead, say "when."
- Pursue small agreements along the way.
- Use vocal "down tones." Do not make it seem as though you are asking questions, but instead making statements.
- Bring in marketing materials if you have them — this demonstrates concrete support.
- Underscore that program design can be flexible and adaptations are easily made.
- Get a commitment to follow up.

5. Following up, as committed.

Workshop Report

Pair & Share Dialogue

Everyone who attended the workshop brought great insight and knowledge about how to engage and be inclusive of people living with dementia. To unlock this expertise and knowledge, participants paired up for a brief discussion. The question they grappled with: **how can you reach people living with dementia and engage them in helping to develop dementia inclusive programming?**

After a short dialogue, groups shared their ideas. The list below summarizes the ideas:

- When people living with dementia are out and seen participating in the community, it normalizes this condition and creates a feeling of acceptance and belonging
- Advocate for acceptance within existing programs. This is especially important for people already involved in programs and wishing to continue to participate after diagnosis. There are many changes with dementia diagnoses. This would be one small way to help sustain existing relationships and routines.
- Adapt existing programs, where possible. In promotional material, clearly communicate how these programs are accessible and inclusive.
- Use word-of-mouth connections. Consider current personal and professional networks, boards, committees, and memberships.
- Ask people with dementia who are already active about what makes participation possible; ask them for strategies to facilitate involvement.
- Use tear-off sheets with program phone numbers available in public spaces
- Promote programs through:
 - Health system allies, including doctors' offices, social workers, Better at Home coordinators, home support workers, social workers, and case managers,
 - Community sector allies, including municipal seniors' committees, faith groups, ethnic groups, farmers markets, community centres, seniors centers, housing co-operatives and senior specific low income housing.
 - Promote at local businesses, such as grocery stores, pharmacies, and cafés.
 - Employ media that are senior-friendly: less digital or online forms and more posters, letters, and paper brochures. The Canadian Association for Retired People's Seniors Health Fair (or other similar events) are great opportunities.
 - Use clever and catchy visual cues.
 - Develop or agree on a "brand" that represents dementia-friendly, like the rainbow for LGBTQ+.
 - Make transportation support available and known.
 - Form relationships with transit providers, like Translink and HandyDart.

Research Update

Alison Phinney & Elaine Wiersma, Building Capacity Project Co-leads
Carlina Marchese & Diana Cochrane, Community Research Coordinators

Alison and Elaine described the asset-based community development (ABCD) approach and developmental evaluation strategy that underpin the Building Capacity Project. Here, the research team is well positioned to help capture progress, learnings, and successes and share them with community partners and other communities that might want to take on a similar approach to developing dementia inclusive community programming. Importantly, the ABCD and developmental evaluation strategy will enable community partners to meaningfully engage in and lead components of the research.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Alison acknowledged the opportunity that the Public Health Agency of Canada funds provide. With these funds, the plan and the vision is to create durable and meaningful community investments, to evaluate the impact of those investments, and make real time adjustments, as needed. A robust evaluation will be undertaken but will be intentionally designed to align with the provider organization's context, capacity, and evaluation interests. The evaluation plan will not be a burden on organizations. Over the coming months, the research team will continue to map out an appropriate evaluation plan as community programs take shape and will continue to consult with the WSH Working Group and NWDWG on the appropriateness of the evaluation plan.



Members of the North West Dementia Working Group and the Building Community Capacity research team at Cecil Green Park House

To support the provision of the community programs, "implementation funds" are available. The details of the implementation funds are evolving but Alison assured that the process to access funds will be low barrier and responsive to community interests and needs. "If you have an idea, let's try it out," she said. Alison detailed that the implementation funds will be divided into two arms: 1) an "engagement fund" with up to \$500 to support community conversations, coalition building, and engagement of people living with dementia; and 2) an "innovation seed fund" with up to \$1000 to enable organizations to build assets and try out programming.

Alison and Elaine envisioned that the Building Capacity Project and the research results that flow from it will lead to policy reform

and sustained investments. As a result, people living with dementia in community will be better supported and more included in community life. Although politicians and policy makers were not included in this particular workshop, over the course of the project the intention is that these stakeholders will be engaged and informed. As a first step, it was important to focus on the community interests and build first from a strong and stable grassroots level.

Alison and Elaine acknowledged their goal of setting up structures so that the project will be able to share our findings across communities. Over the next few years, they imagine that large and small-scale meetings will take place to communicate findings and successes and to continue to engage and be informed. To support this work, Carlina and Diana are in place to build networks and relationships with stakeholders. Carlina and Diana will lead asset mapping within each community to better understand the landscape and context in which initiatives are seeded and launched.

Carlina and Diana provided a brief update about the asset mapping process and outlined next steps. Through the asset mapping exercise, they are looking at ways to foster inclusivity, identify resources, offer training, seed ideas on supportive and inclusive programs, and promote organizations that have something to offer, among other items. Ultimately, they want to ensure longevity of the initiatives and the Building Capacity Project implementation fund. "We want to set up a situation where programs can be self-sustained beyond the short term funding and supports." In the near term, they will focus on launching the implementation fund and engaging with communities on how to access and use it. Drawing on the asset maps and using the innovation fund, partners will be supported to innovate and to build on success, as well as learn from setbacks.

Workshop Report

Capturing the Learnings

Workshop attendees gathered in small groups to address how they can initiate and enhance dementia inclusive initiatives in their community. To surface ideas, workshop attendees explored the following questions:

1. What are some successful features of inclusive programming and community opportunities for people living with dementia?
2. What are the barriers to successful dementia inclusive programming?
3. What facilitates successful dementia inclusive programming?
4. How can organizations build on their strengths to create opportunities that are dementia inclusive?

Below is a summary of the ideas that emerged from those discussions, organized by themes.

Successful features of dementia inclusive programming

Education and advocacy

- Educational initiatives that are led by people with dementia and their care partners, where presentations draw on their own experiences, can be a powerful approach for raising awareness and addressing stigma.
- Dementia education within training programs for health care as well as community program providers are a great way to ensure that those who interact with people living with dementia are skilled and informed. With this knowledge, these providers will carry the torch and can make real time changes within their practice.
- Advocating for help and education for care partners is essential. A care partners' ability to navigate options and accessing information predicts what the person living with dementia may have access to.
- "Train the advocate" program where people living with dementia can be supported to advocate for themselves in ways that fits their preferences and personalities.

Support groups

- Support groups do not all look the same. They can be different to what is typically thought of – sitting in a circle taking turns airing one's issues and ruminating on 'the diagnosis,' for example. Myrna suggests comparing groups and choosing one based on your preference. If what you prefer does not exist, advocate for it.
- Do not narrow the focus on dementia only. Where possible, offer participants support in other ways.
- Support groups are not for everyone – and they should not be expected or mandatory. Some prefer one-on-one support or prefer to deal with transition and issues in their own ways.

When asked about activities for people living with dementia, the majority of workshop participants who responded to the survey indicated social programs, anti-stigma, and educational activities are of greatest interest.

Dementia cafés

- Cafés are part of a larger movement to destigmatize dementia, giving people purpose and a sense of belonging in the larger community.
- Refreshments are available and in some cases information and educational materials are provided.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

- When setting up a café, consider these main elements: right place, the right partner, at the right time. Getting any one of these wrong can undermine the success of the café.

Physical, social, and creative activities that are 'in the moment'

Below is a list of inclusive programming features for people living with dementia as they allow people to participate in the present moment and do not require previous knowledge or expertise:

- Field trips, like park walks and history tours
- Observational tours in museums
- Music. Many people would be willing to share their talents in programs, if asked. Myrna and Clara underscored the value of music. Clara said, "If I am having a bad day it turns everything around."
- Visual arts as it can be expressive, engaging, and can be done year-round.
- Social gatherings over food, like a dementia café. Additional programming ideas could grow through the dementia café.

Joint Respite

- "Joint respite" shows promise as a programming option where both the person living with dementia and their care partner have dedicated program components, either together or independently.

Normalize experience – and focus on the present

- When welcoming new participants who are living with dementia, engage in a way that you would with anyone you would like to get to know more. Learn about what makes them unique, what make them feel welcome in that facility, and what kinds of activities draw them in.
- Programs are most successful and rewarding for people living with dementia when they are designed around being present in the moment and when it focuses on the abilities of people living with dementia (versus planning for something in the future or that might strain their physical and/or cognitive abilities).
- Programs must create an environment where people can "see themselves", and see healthy examples of others living well with dementia.
- Programs should strive to create an atmosphere that is welcoming and where people feel like they belong.



Members of the North West Dementia Working Group, West Side Seniors Hub, and Building Community Capacity research team at Kitsilano Neighborhood House

Flexible and accommodating

- Programs and approaches need to be dynamic and fluid to remain inclusive, supportive, and effective as people progress in their diagnosis.
- Consider building a 'bridge program.' When people's needs and abilities change they may not be able to participate in the original program they selected, but might benefit from another program that does similar things and where there may be some of the same people involved. The transitional programming at MoMA is a good example
- Program design and offerings need to acknowledge the fact that no two people living with dementia are the same.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Start small

- Successful or promising innovations often start small and first aim to create an inclusive, welcoming atmosphere (e.g. by hosting a Dementia Café); further ideas can emerge out of this initial success.

Laughter, fun, and food

- Clara advocates for humour. Being together and having fun motivates participation.
- As Nita said, the point is to come together and have fun – and end with ice-cream!

Technical considerations for successful dementia inclusive programming

Capacity and training

- Few paid staff roles, which are key for consistency and getting things done; much work depends on the contribution of volunteers, which can be demanding and does not provide the needed consistency.
- Recruitment of volunteers – in many cases organizations face a shortage of volunteers, so relying on volunteers to support programming is not realistic.
- Concerns on burden of additional programming on staff who are already working over capacity.
- It is critical to be properly prepared to support people living with dementia; think about what kinds of training exist to support program providers and volunteers? Draw on successful models such as the Dementia Café training in Thunder Bay. Draw on Alzheimer's Society training resources. Incorporate the lived experience of people with dementia in all training approaches.

Safe, accessible, and welcoming spaces

- Limited access to space and when space is available, it isn't always the right design.
- Finding the right venue, or right partners can be difficult at the outset, so innovators must be prepared to reflect on setbacks and develop a "Take 2" that addresses these challenges (e.g. NWDWG's first attempt at a Dementia Café was a "flop."
- Ability to create a safe space – both physical and emotional safety are important.
- Space is not cheap but sometimes it can be free! Always ask! Unless you ask you will never know – maybe the community centre can provide space in-kind or they may know of another venue that would be even better.

Transportation

- Lack of access to appropriate transportation is a major barrier to participation.
- Think about how transportation needs may be different within different communities. Transit based and car-based communities may need different transportation support strategies.

Adaptation and implementation

- Many organizations are unsure of how to adapt existing programs to be more dementia inclusive – what can be changed and how can these changes be managed?
- There are numerous ideas out there, but when basing one's own programming ideas on other programs it can be challenging to understand the ins and outs of the model, so network closely with innovators, draw on their resources (e.g. toolkits) but be prepared to make adaptations based on your local context.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

Rules and regulations

- Many health care workers want to be more responsive to the needs of people living with dementia, but the regulations, licensing, and work portfolio expectations do not allow for this.
- The health care landscape, or the community at large has policies (e.g. bylaws) that make it difficult for new programs to take root, so innovators must be prepared to experience frustrations and be ready to be entrepreneurial (e.g. Paul's Club's, found a way to get around being classed as a "restaurant").

Funding and financial resources

- Identifying funding sources for new programs can be challenging. Consider draw on and adapt existing community assets instead of, or in addition to, creating something brand new.
- If making adaptations to existing programs, build information about accessibility and inclusion into promotional materials.
- Think about "how to make the case" to potential community partners using strategies developed by Momentia.
- Cultivate sponsors and champions from inside and outside the system and organization.

Sustainability over time

- Funding is challenging to maintain. By building comprehensive program evaluation into funded programs and communicating results using both statistics and impact stories (or other creative approaches) the chances of being refunded, attracting donors, or being successful on a next grant application are increased.
- Adapting existing programs to be more inclusive of people with dementia is a great way to overcome funding scarcity and integrate people living with dementia into common community experiences. However, it can create extra pressure on personnel. To do this integration well, staff must also be provided with time to plan, develop, and implement these adaptations.
- Adapted programming is not always accessible or safe for people living with dementia, so programs must also allow space for care partners.
- Cost barriers should be seamlessly addressed and built into programs. For example, program fees should be low or programs should be free. Transportation support, including coordination and costs should also be factored.
- Ensure that there is something fun and meaningful for care partners to do (e.g. by providing concurrent programming for partners, like the Frye Museum does). This way both the care partner and the person living with dementia will be motivated to return.
- The needs of people with dementia can shift over time. Certain individuals may no longer be able to participate in the program as they previously have. In the design of a dementia inclusive program, anticipate the need for a transitional strategy (e.g. the "Bridge Program" offered by the Frye Museum).

Start with what is already in place

- Grassroots approaches build on the assets and strengths already in place in the community and participating organizations.
- Experiences and examples from other places can guide and inspire the development and implementation of program, but local level context, capacity, and need must underpin any effort.
- Do not be afraid to ask what people living with dementia need to feel compelled to join, to feel included, and to feel safe. They are local level experts – include them in planning and design of you initiatives.

Building Capacity for Meaningful Participation by People Living with Dementia

A Project under the Public Health Agency of Canada's Dementia Investment Strategy

Workshop Report

- Ideas on how to make existing programming more accessible and inclusive of people living with dementia were shared. Working with existing programming enables organizations to start with what they are already doing well.
- Funding from the Building Capacity Project will help test and scale programs. The project can help share the story of how these programs developed.
- Workshop has highlighted the merit of a "bottom up approach". With this approach, stakeholders, service providers, and people living with dementia can gather ideas and community assets and identify outcomes that matter. Together they can build and lead a program.

Communication and promotion

- Grow public awareness of the prevalence of dementia. De-mystify the diagnosis and break down stigma to help create acceptance and to welcome participation.
- Engage policy and decision makers and funders to garner support and profile. Here is where program evaluation and research findings will help to engage and build credibility for the community development work and programmatic contributions. There may be a benefit of targeting specific boards (i.e. health authorities, hospital foundations, municipal councils).
- Build on people's personal connections to dementia. It has touched the lives of so many.

"Listen to what persons with dementia enjoy, use neighbourhood assets and keep it simple"
Comment from Workshop Participant, Post Event Survey

"Stop thinking about impossible things, start thinking about possible things! The 'Come Alive' intervention in the health service sector is a great example of what is possible."
Comment from Workshop Participant, Post Event Survey

"Doing something is better than doing nothing because of a fear of failure."
Comment from Workshop Participant, Post Event Survey

Closing Remarks

As the workshop ended, the overall feeling was one of gratitude. In a closing dialogue, participants expressed how grateful they were for the new connections, new knowledge, and for the full participation of everyone in attendance. The workshop achieved the aim of building relationships within and across the Westside Vancouver and Thunder Bay communities. It also provided space for community leaders to consider how best to move forward in their context.

Among collaborators, there was some skepticism about the value of a workshop. The financial costs seemed high to some people. However, the workshop experience exceeded all expectations and facilitated important connections between ideas, issues and people that will support meaningful actions for her and the Building Capacity Project as a whole. It was worth the investment. The richness and depth of insights and the conversations will propel the Building Capacity Project forward. Without the workshop there would have been no mechanism for uniting stakeholders across sites. The building blocks of a pan-Canadian coalition of dementia-inclusive program developers, providers, and evaluators has started to form – a coalition fully inclusive of and guided by people living with dementia. This coalition is well positioned to make a significant difference in the lives of people living with dementia for years to come.