



Building Community Capacity for Dementia Inclusion: An Action Guide

SUMMARY

2025



Building Community Capacity for Dementia Inclusion: An Action Guide is
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It was co-created by the Building Capacity Project's Community
Action Team, comprised of advocates with lived experience, care
partners, community partners, and research team members. It
was facilitated by Andréa Monteiro and Eric Macnaughton, with
support from the Building Capacity Project research team, co-led by
Alison Phinney and Elaine Wiersma.

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What is the guide, and how did this guide come about?

Welcome to Building Community Capacity for Dementia Inclusion: An Action Guide, a practical resource offering best (or promising) practices for building community capacity for dementia inclusivity.

The guide, created from the learnings of Building Capacity Project partners, aims to support groups and communities in their efforts to address and reduce stigma, and become more inclusive with their activities and programs. It is a tool to provide support and direction for communities and organizations who want to create meaningful opportunities for people living with dementia to remain active and connected in their communities through creative activities, social involvement, physical exercise, and volunteerism.

The Action Guide was co-designed by a Community Action Team (CAT) consisting of people living with dementia, care partners, community champions and researchers. These CAT members met monthly for a year and a half and, through a collaborative and generative process, brought this resource to its fruition. Now, the Action Guide will support local community-based organizations in creating dementia inclusive and person-centred approaches for programs and activities that support meaningful participation of people with lived experience of dementia. This includes everything from partnership development, community engagement (including people living with dementia themselves), and visioning/ planning, to active implementation, evaluation, sharing knowledge with the larger community, and sustainability. **This Guide is a living document that we envision will share its learnings about implementation through a virtual network, so everyone learns from each other in real-time.**



The Audience: who will benefit from the guide?

The kinds of groups who might find this resource useful include seniors (or 55+) serving centres, Neighbourhood Houses (also known as Settlement Houses), advocacy-oriented action groups, community connectors (including those working with primary care teams), recreation centres, adult day programs, other Non-Governmental Organizations from the community-based seniors sector, as well as grassroots entities such as local residents groups and faith-based organizations. The guide will also be useful for Municipal task groups leading dementia-inclusive or age-friendly strategies in their community. Whether you're based in a bigger community with more resources, a smaller city, or a close-knit rural town, this document addresses relevant principles and strategies that can be applied across distinct contexts. The Guide can also support individuals hoping to deepen their knowledge and understanding of asset-based community development work and gain insights on engaging people with lived experience.

How to use the Action Guide: how should we decide whether the summary or the full version is right for us?

The guide has two versions, the summary (this one) and the full version. The summary serves as a roadmap to the different phases of moving an idea into action. The full version takes you through each phase with the help of a case study and a detailed resource section. The full guide can be used as a reference tool for groups that have already been doing similar work that they'd like to revitalize. Alternatively, if your group is ready to start something new, you can go through it in sequence, one module at a time, or in any order that applies to your context. Keep in mind that though the Action Guide is written as a series of modules, moving your idea into action is really an iterative, circular process, as the topics of the later modules, evaluation and sustainability, also need to be considered from the beginning.

If you're unsure of which version to use, ask yourself key questions like:

Are we just curious about dementia inclusivity, or are we ready to "do the work"? If the answer is "just curious", the summary is for you. If you're still unsure whether you're ready to move beyond the summary to a deep dive into the full Action Guide, ask yourself some further questions about whether you're ready to consider the following issues:

- **Have we established solid relationships with people also wanting to build something?** (Module One helps you think through initial partnership development)
- **Are we committed to engaging people with dementia, but not sure what's possible, or how to do it?** (Module Two helps you understand “the ladder of engagement, while Module Three helps you address stigma as you open up a community conversation about initial ideas, and think about who your initiative will serve)
- **How will we brainstorm our initial ideas and come up with a plan?** (Module Four helps you consider what assets you have to draw on as you start developing a plan to move towards your vision)
- **How will we move forward with our plan?** (Module Five helps you develop a concrete implementation strategy that draws on strengths from within and outside of your group)
- **How will we know if our initiative is on the right track, and if it's making a difference?** (Module Six outlines the key questions to consider when planning an evaluation)
- **How will we sustain our initiative?** (Module Seven helps you “tell the story” of your endeavour and develop other strategies to strengthen and grow your initiative).

Regardless of which version you choose, the Action Guide provides an overview of each phase of moving your idea into action, and outlines a set of strategies and principles to consider for each stage. In the case of the full version, it illustrates the strategies and principles with real-life case studies to help readers get a stronger sense of what those look like on a practical level. It also provides a portfolio of learning resources to help community partners develop new initiatives and make their existing programs and spaces more inclusive of people with lived experience of dementia. In the long run, the Action Guide is intended to be a living document which will hopefully stimulate a wider range of groups to become part of a community of practice doing similar work, for and with people living with dementia.





○ Module One ○ Partnership Development

The partnership development stage of any community intervention is the foundation of everything that follows. This is where community partners (e.g. community members, community-based organizations, researchers and community developers) and research teams come together and take the time to build strong and effective working relationships, and develop a shared understanding of the project's objectives and of the process for carrying those out.

The key messages in this module are:

- **Identify partners who are ready and motivated**, and for whom the initiative is a passion project
- **Host an initial get together or event where the partners can share a meal** and move towards a shared understanding of what they'd like to do together, and how they're going to do it
- **Bring strong facilitation skills so that diverse practices and perspectives can be acknowledged**, and to foreground perspectives that could otherwise be overlooked, including the those of people living with dementia themselves
- **Acknowledge that the relationship between you and your partner is integral to the work that you will do together**, and take time to build and foster it



Module Two Community Engagement

The principle of “nothing about us without us” speaks to making sure to meaningfully involve people with dementia in the process of moving your idea into action. It’s important to develop an intentional approach around this and understand that involvement can mean different things to different people and can depend on where someone is on their dementia journey.

Engaging people with dementia is something that takes time to do respectfully and meaningfully, and it has taken a while for many community groups to become skilled and confident about doing it. Training and mentoring, including from people with lived experience themselves who are experienced speakers and advocates is part of helping your organization become better.

The key messages in this module:

- **Develop a strategy to establish referral pathways between your organization and other places** where people with dementia receive support, for instance through social prescribing community connectors
- **Develop an inclusive messaging strategy, and a fun, social atmosphere** where people with dementia are active and “living well,” and so that other people with dementia are motivated to come out and keep coming back
- **Recognize that there is a “ladder of engagement” that can start with basic ways of opening up a conversation and taking advice** (for example, holding a focus group about a possible new program, or simply listening to participant feedback about an existing one)
- **Becoming more confident about engagement takes time**, and will benefit from training and mentoring, including from experienced advocates with dementia
- **As your organization becomes more skilled, and people with dementia themselves become ready, you can move up the ladder of engagement**, for instance, establishing a working group of people with dementia and care partners.



○ Module Three ○ Convening a Community Conversation

The Building Capacity Project is grounded in Asset-based Community Development (ABCD), an approach which builds upon the strengths the community already has, such as resources, places, relationships, and people, including people living with dementia. To realize the full potential of the ABCD approach in this context, it's very important to convene a community conversation about dementia. This helps partners understand more about the condition, including the stigma that so often surrounds it. And it helps them engage people with dementia from a strengths-based perspective.

The key messages in this module:

- **Hosting a community conversation is important for helping community partners understand how to become more supportive and inclusive of people with dementia**, and to address the stigma that can prevent them from engaging people from a strengths-based perspective
- **Community conversations should provide training about dementia from a biomedical as well as an experiential perspective**, and should have people with dementia playing leading roles
- **Together with training from the Alzheimer Society, resources such as the Flipping Stigma training, Through Our Eyes, and the BCP Cards are valuable training and conversation starter resources**
- **By convening a community conversation, partners can become more knowledgeable and confident about how to make their resources more inclusive**, can identify some initial ideas for doing so, and can set the stage for moving these ideas into action.



Module Four Visioning and Planning

Once you have explored some initial ideas and are ready to move ahead with your initiative, the next module will help you clarify your vision and articulate a more concrete plan for how that initiative will develop and what the outcomes might be.

What do you want your organization or program to look like? What's going to change to make your organization more inclusive? Will it mean adapting an existing place or space, or will you develop something entirely new? Whatever the case, it's paramount that the process for visioning and planning include people with dementia and their care partners so they can take an active part in shaping the initiative.

In order to help partners think through these questions, the BCP project provided various resources, including training and networking events so partners could envision possibilities and understand principles underlying other successful initiatives. It also provided 1:1 coaching as well as seed funding to help them develop a plan that identified their broad objectives, as well as mapped assets to facilitate planned activities, and identified ways that the seed funding could foster these.

Key messages in this module:

- **Participating in training and networking events enables partners to envision possibilities,** and to understand key design principles underlying other successful initiatives
- **Key design principles include empowerment of people with dementia,** creating a sense of connection, and fostering an experience of joy based on fun, social activities which emphasize being present in the moment, but which are not seen as patronizing
- **Programming should strive towards being inclusive:** of people from various ethnocultural backgrounds, of people at various points on their dementia journey, and of people and care partners
- **Developing a more concrete plan involves mapping available community assets** (people, partnerships, space, seed funding, coaching, training, networking, etc.) that can be draw upon towards moving a specific idea into action.



○ Module Five Implementation ○

Now that you've got a plan, the next step is to put it in place. The implementation module takes you through all the considerations involved in making your vision a reality.

Key Messages in this module:

- **Identify a champion** for whom the initiative is a passion project
- **Share the leadership**, by finding ways for the champion to enlist the support of others, including senior leaders who can "open doors", as well as point people, for instance practicum students, who can drive the initiative
- **Mobilize assets that are a good fit with your initiative** (e.g. selecting, training and supporting the right staff, finding partners that share similar goals who can support and mentor you if necessary, and finding the right space)
- **Nurture confidence**, by starting small, putting something in motion, reflecting on progress as you grow, and being ready to adapt to changing circumstances or unanticipated issues



○ Module Six ○ Evaluation

Over the long term, evaluation helps you know whether your initiative is reaching the audience you intended, and whether it's having the desired impact on their lives. Short term, evaluation helps you know whether your program is firmly in place and highlights any barriers getting in the way of implementation. It also helps you understand how your program works, and homes in on which program elements or principles seem to be most important for success. This approach of "evaluating as you go", and shifting and tweaking the process, is known as developmental evaluation. Developmental evaluation bears in mind that you won't always know what your desired outcomes are, and that these longer-term visions will emerge and become clearer over time. The focus is on learning along the way about what's working well and what you could be doing better, fine tuning in real time to ensure you're making a difference in people's lives.

Key messages in this module:

Because developmental evaluation is a flexible, emergent approach, there are no specific "steps" for doing it. Nonetheless, when considering your strategy, consider and address the following issues:

- **Who are your primary information users and what are their priorities for evaluation questions** (understanding key design principles and valued outcomes; understanding the program's reach and impact; understanding how to adapt the program to a new context?)
- **Where are you in the innovation cycle** (invention, growing/adapting or scaling out)?
- **What methodology is appropriate?** (qualitative, quantitative, or mixed methods?)
- **What will the timeline be for the various phases of the evaluation process** (questioning, observing, analyzing, and summarizing the findings?)
- **In order to answer these questions, consider setting an evaluation steering group that comprises your key stakeholders**, so you can identify the key evaluation questions, co-create the evaluation questions and develop a methodology that addresses these, and a timeline for collecting and analysing the data.
- **In addition to standard ways of producing evaluation results (e.g. a written report), think about using creative ways of "telling the story" of your initiative, and the community that it's embedded within** (for example, case studies, or "impact stories," or using video or photographic ways of capturing what's going on).



○ Module Seven Sustainability ○

In previous modules, this guide lays out how to mobilize your idea into action and evaluate whether it's working. Now, in this final module of the guide, it's time to consider sustaining it over the long term—transforming your initiative from a pilot project into a regular ongoing part of “the way you do business.” That may involve scaling your project out to reach new people or communities. And it may mean providing evidence, making the case to policy makers and funders as to why they should continue investing. Sustainability is about helping community capacity-building initiatives mature, thrive, and even expand.

Key messages in this module:

- **Build sustainability into the design of the initiative** through an asset-based community development approach
- **Use evaluation to tell the story about “what works”**, drawing on an integrated knowledge translation approach to build and draw on an informal network of advisors/champions to craft key messages
- **Develop knowledge products** (such as an interim report, a case statement of emerging findings, project documentary, etc.) before the formal end of the project, which use stories and numbers, (giving human context to statistics) and tailoring these to what resonates with your audience (including potential allies and funders)
- **Look for emerging opportunities to align with internal organizational priorities, and new external policy windows** like “healthy aging in the community,” and forming coalitions with partners doing similar work to influence the policy and funding climate
- **Use implementation science principles** (e.g. tools like the Action Guide, training, technical assistance, and networking) to scale out the approach to new settings and communities

Building Capacity Project Action Guide co-authors:

Community Action Team

Danna Garcia, Executive Director, South Granville Seniors Centre, Vancouver, BC
Bill Heibein, Dementia Advocate, Co-Founding Member of the North West Dementia Working Group, Thunder Bay, ON
Karen Hunter, Retired Nurse, West Point Grey United Church, Vancouver BC
Lynn Jackson, Dementia Advocate and Research Advisor, Sidney BC
Thais Lopes, Seniors and Housing Coordinator, Kitsilano Neighbourhood House, Vancouver, BC
Farhad Farhangfar, Co-founder, Dementia Co-Creation Academy, Burnaby, BC
Faryar Mohammadi, Co-founder, Dementia Co-Creation Academy, Burnaby, BC
Myrna Norman, Dementia Advocate, Purple Angels Dementia Ambassador. Maple Ridge, BC
Lois Tobin, Care Partner, Member of the North West Dementia Working Group, Thunder Bay, ON

Building Capacity Research Team

University of British Columbia, Vancouver, BC
Alison Phinney, PhD, Academic Lead
Eric Macnaughton, PhD, Project Manager
Andréa Monteiro, PhD, Community Research Director
Ania Landy, PhD Student in Interdisciplinary Studies, Community Research Coach
Sheila Novek, Postdoctoral fellow, evaluation researcher
Samantha Pineda Sierra, MFA, Visual Communication Designer
Heather Neale Furneaux, MFA, Knowledge Mobilization Lead
Paulina Malcolm, MSc Student in Rehabilitation Sciences, Community Research Coordinator

Lakehead University, Thunder Bay, ON
Elaine Wiersma, PhD, Academic Lead
Nisha Sutherland, PhD, Co-Investigator
Carlina Marchese, MHSc, Knowledge Broker
Jiaqi Li, MEd, Research Coordinator

