



“The 5-year grant period is over before you know it”: Rethinking sustainability planning for enduring community-led dementia friendly interventions

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Introduction

In collective impact initiatives, the sustainability of collaborating organizations' programs is the cornerstone upon which the legacy and lasting impacts of the collective impact are built. However, the main challenge lies in maintaining the momentum and funding beyond the initial project period. Organizations operating in small towns and rural areas may face particular challenges because of the dearth of stakeholders with the capacity to sponsor projects for extended periods. Hence, exploring additional pathways for longevity is vital for organizations to ensure sustainability.

Purpose

To identify organizational and community options to sustain project impact beyond grant period.

This paper draws on the Interventions to Enhance Social Inclusion of Older Adults with Dementia in Saskatchewan, a five-year project (2019-2024) funded by the New Horizons for Seniors Program (Employment and Social Development Canada).

The project has funded 08 Collaborating Organizations (COs) to implement interventions that promote awareness and enhance social inclusion of older adults living with dementia in small towns and rural communities in Saskatchewan.

Methodology

We interviewed 24 participants from Collaborating Organizations (11 interviews), Community Table (6 interviews), Advisory Committee (3 interviews), and Backbone Management Group (4 interviews) between February and April 2022 via Zoom. [1]

Data analysis: We employed a thematic framework analysis using a combined approach (deductive and inductive analyses) and focused on the factual and non-factual statements expressed in our interviews.

[1]Results presented here constitute part of a process evaluation, which analyzed the capacity of collaborating organizations to obtain resources to continue project operations, maximize the untapped potential within their communities and adjust their procedures to sustain dementia-friendly services

Findings

Rethinking Sustainability

Apart from relying on guaranteed funds, Organizations can sustain certain dementia interventions by adjusting their organizational operations and maximizing resources within their communities:

Beyond business as usual for organizations

Re-evaluate the experience of the target population and adopt measures that enhance dementia awareness within other organizational operations.

Apply lessons learned about dementia-friendly initiatives that improve public awareness.

"...we can't continue this program the way that it was. But we now know things we didn't know before. And we do know that there's a need...so is there a way that we can integrate some of this into our other programming...they can take their learnings and experiences and apply them consistently on an organizational level. Even if this program never comes back in the way that is currently being ran, that to me is sustainability. Because the system has worked something and is applying it..." Collaborating Organization Representative

Leveraging community assets to promote and maintain dementia awareness
Smaller rural communities often have a solid network system that can provide a platform to collaborate with the community after project activities end.

Organizations have the opportunity to utilise these network systems to disseminate dementia relevant information, and maintain activities that improve public awareness, foster social inclusion and reduce the stigma and social isolation associated with dementia.

Faith based institutions, Recreation centres and Primary Healthcare Institutions count as major stakeholders within these networks:
Example: Staff in Primary Healthcare offices can display or hand out material about organizations providing dementia related services in the region.

In rural communities, it is *"...not so much what you know or what you're trying to give, it's who you know, and who's gonna back what you're about."*
Collaboration Organization Representative

Organizations can successfully advocate for practical measures for persons living with dementia because local authorities are more likely to welcome proposals that create an inclusive environment for the whole community:

"...if you make a facility, you know, accessible with the ramp, well, that's good not only for seniors, but also people in wheelchairs, also mothers pulling pushing strollers...the whole broadness of some of the stuff that we do around making things Age Friendly for seniors, does support accessibility through the whole lifespan, and for others." Collaborating Organization representative

Conclusions

In the face of the limited availability of dementia care resources in rural communities, and increasing health and caregiver costs: Avenues exist for organizations to build relationships with several partners in the community to sustain dementia awareness initiatives, thus promoting a more dementia friendly environment.

For some organizations providing dementia care services, public support is crucial for sustaining program activities beyond the project timeline and guaranteeing continued impact.

Acknowledgements

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The City of Yorkton

SaskAbilities

Alzheimer Society of Saskatchewan

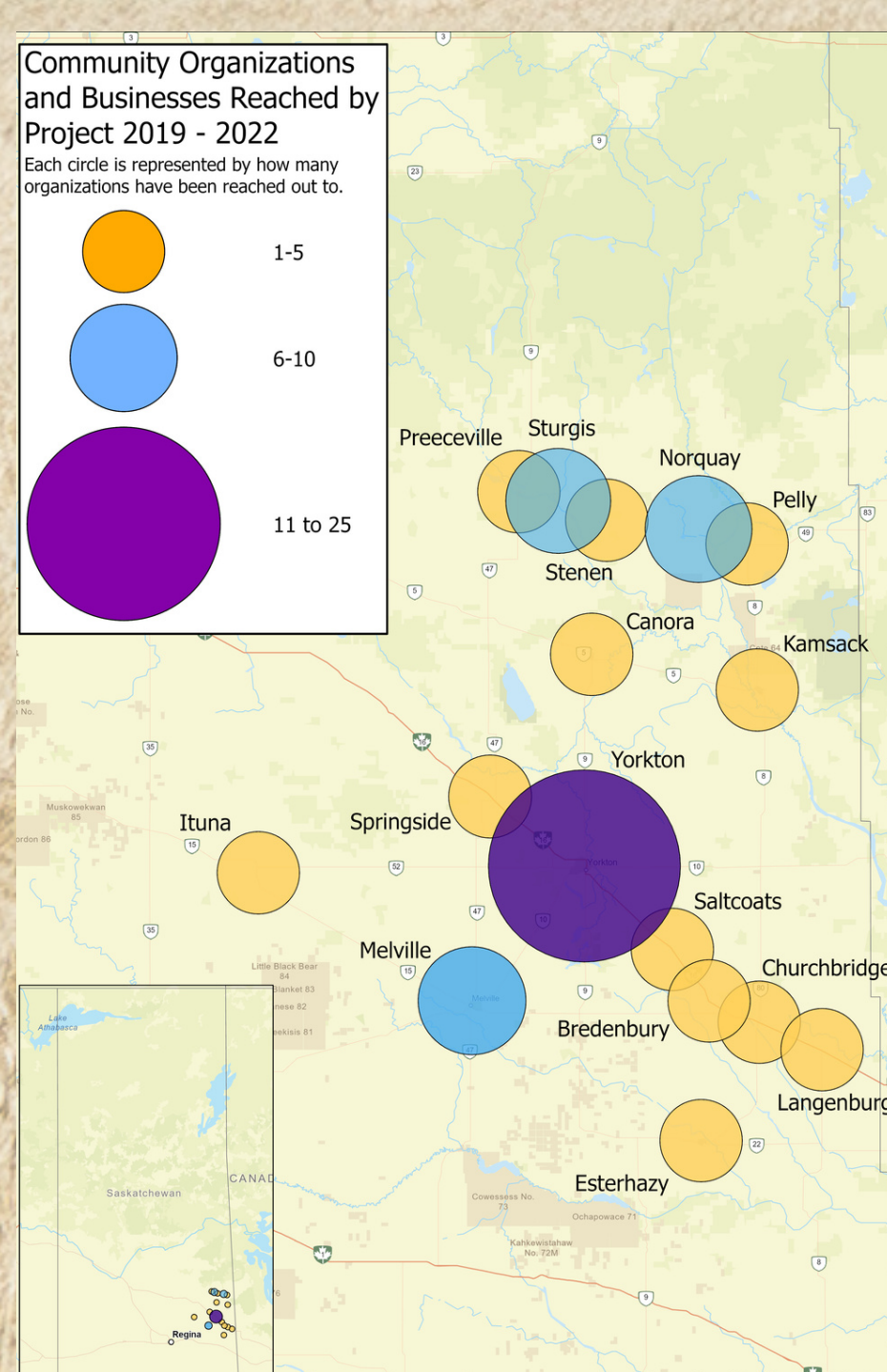
Godfrey Dean Art Gallery

Parkland Valley Sport, Culture and Recreation District

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Engagement of persons with lived experience of dementia in designing, implementing, and evaluating community-driven programs

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Introduction

The powerful slogan of “nothing for us without us” has been widely adopted in policy and practice change efforts to reinforce the opportunities for people with lived experience (PWLE) to be meaningfully engaged. Despite these efforts our knowledge of effective engagement practices is somewhat limited. The meaningful engagement of PWLE of dementia is arguably an untapped resource in research (Snowball et al., 2022) and policy and practice domains (Milton, 2016).

Objectives

To contribute to the learning about effective engagement strategies, we report on the activities and processes we have been employing during a Collective Impact project that addresses the necessary supports for persons with dementia and their care partners in rural Saskatchewan. *Dementia Supports in Rural Saskatchewan* is a five-year (2019-2024) initiative that is funded in part by the Government of Canada’s New Horizons for Seniors Program. This funding has supported our team to distribute funds to local organizations to implement individual, community and organizational interventions that promote awareness, reduce stigma and enhance social inclusion of older adults living with dementia in small towns and rural communities in Saskatchewan.

Methodology

The data presented here are part of an ongoing evaluation of the overall initiative and are drawn from observations, document reviews, and interviews across the funded projects. Our analysis used qualitative approaches to summarize some of the key areas where we have engaged persons with dementia and their care partners in various levels of the project.



Findings

Our findings suggest 5 levels of engagement (individual, service/program, organizational, community, and policy) and strategies used at each level to capitalize on the tacit knowledge of PWLE of dementia in the design, implementation, and evaluation of community-driven programs.

Individual: Effective individual strategies **use a person-centered approach** to support the person with dementia in the shared-decision making to tailor services based on their needs and preferences

Persons with dementia in a community-based art program determined how they wanted to be involved:

“It was really organic. You both melded with us and our family. You were both very open. Didn’t have any preconceived ideas of what we should do. But open to what we have in mind. You both came with great ideas, too.” Care partner/Artist, Godfrey Dean Art Gallery project

Every person with dementia with the SaskAbilities Dementia Friendly Life Enrichment project has a person-centered plan which is updated regularly. Facilitators use the plans to organize individual and group activities for PLWD and their care partners. The person-centered care plan is a tool that can be adapted for home care and day wellness programs that provide services to persons with dementia.

Service/Program: **Engagement of persons with lived experience in the design of services** and programs can ensure that these are appropriately tailored to the needs of persons with dementia and their care partners

The Godfrey Dean Art Gallery consulted PWLE of dementia in the community for the design, implementation and ongoing evaluation of the Belong Where you Find Yourself Project that aims to promote social inclusion, improve public awareness and reduce stigma around dementia through art creation and exhibition.

Organizational: Engagement as **active members of the Advisory Committee** in providing advice and direction on the most appropriate interventions to support in rural areas

The project lead sought advice on reviewing and supporting the co-design of the Godfrey Dean Art Gallery project.

Community: We have **engaged with a network of community leaders/members** through our Community Table meetings in order to provide a platform for stories of lived experience of dementia

“...the most engaging stories for learning are lived experience stories. So, I think that [engaging persons with lived experience in the community table meeting] was a good idea to use that. And it doesn't matter if you're an expert in the area, hearing of someone's lived experience view is always, you know, interesting and beneficial. Just you know, continuing that model. People remember better when they have stories and emotional connections to it.” Advisory Committee member

Policy: Engaging people with lived experience of dementia in **advising on specific policy changes** that should be implemented by municipal government

We engaged two couples with lived experience with the City of Yorkton Audit Program:

“We as people that work in our facilities, and in some instances, some of my colleagues have grown up in these facilities, if they played hockey or have been swimming, they don't see the built environment in the same way as outsiders. So it [engaging persons with lived experience in the audit program] gave us some concrete examples, in a way that was very valuable.” Manager of one public facility

Conclusions

The findings can be used as a framework to support organizations in redefining their engagement practices and rethinking how to meaningfully and sustainably engage PWLE in designing, implementing, and evaluating programs and in leading organizational policy and practice change. This poster describes some of the strategies that were used but what is still needed is an evaluation of the effectiveness of these strategies from the perspective of those with lived experience.

Poster presented at the 52nd Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG2023), Toronto, Ontario, October 26-28, 2023. Poster design by S. Mc Gee.

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