POLICY *Brief*

▶▶ Enhancing Social Inclusion for Older Adults Living with Dementia:
A Community-Based Collective Impact Approach in Rural Saskatchewan

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"My husband was diagnosed with Alzheimer's disease. One Sunday, I was not feeling well and decided to stay home from Church so he went to Church himself. When he returned home he was upset. "Not one person spoke to me at Church today", he said. We knew most of these people and considered them our friends. I was surprised at how my husband was treated and so I spoke to the Pastor. The next Sunday and every Sunday after that people made a deliberate effort to come and speak to my husband.

These people in Church did not intentionally ignore my husband. They didn't know what to say to him. So they said nothing. He felt ignored and isolated. We must find ways to inform people about this awful disease and provide programs to include people with dementia. Otherwise these sufferers and their caregivers will continue to feel isolated, ostracized and alone."

- Advisory Committee Member, Dementia Supports in Rural Saskatchewan Project

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The social isolation of older adults, especially those living with dementia, is a global challenge and Canada is no exception. Most factors that contribute to social isolation among older adults are systemic, such as the stigma of dementia, ageism, poverty, and inadequate access to resources and supports. A new initiative from the Saskatchewan Population Health and Evaluation Research Unit (SPHERU) is working to reduce the stigma and enhance the social inclusion of older adults living with dementia and their care partners in rural Saskatchewan.

With funding from Employment and Social Development Canada (ESDC), SPHERU is assisting community-based and civic organizations to develop, implement and evaluate interventions that will take place at individual, community and organizational levels.

This five-year initiative (2019-24) will implement and assess multiple interventions across these three levels in small cities and rural communities of Saskatchewan. Funds flow from SPHERU to Collaborating Organizations (community-based organizations, municipalities, businesses, service delivery agencies, etc.), to deliver the

interventions. Collaborating Organizations agree to work within a collective impact approach for both delivery and assessment of the intervention.

Given the limited policy literature on collective impact, this Policy Brief outlines the design and implementation of a collective impact initiative and draws out potential policy implications. There is a wealth of literature on multi-sectoral (or inter-agency) collaboration and coalition-building that centres, for the most part, on breaking down silos in government. Collective impact, however, mostly targets the non-profit and community sector and is not well-documented in the policy literature.

What is Collective Impact?

The term collective impact was first introduced in an article published by John Kania and Mark Kramer in 2011 in the Stanford Social Innovation. Collective impact refers to social reforms that involve the commitment of a group of actors from different sectors to a common agenda for solving a specific complex social problem, using a structured form of collaboration. These multi-sectoral collaborations provide a framework to achieve systems-level changes in communities. It is premised on the presence of influential champions willing to commit to action on a specific issue, a shared perception of the urgency of the issue across sectors and organizations, and the availability of adequate resources to fund and implement the interventions and to support the work of the collective. Collective impact is a structured approach to problem solving that includes five core elements.

Why Dementia and Why Rural Saskatchewan?

Saskatchewan's 1.1 million residents live in a geographic area the size of France (Hall & Offert, 2015). One-third of that population live in rural towns and communities, making it the second most rural province in the country. Age is the greatest risk factor for developing dementia, and the number of Saskatchewan residents aged 55+ is rising (Moazzami, 2015). Further, a recent study found that dementia and cognitive impairment are more prevalent among rural seniors than urban older adults (Weden et al., 2018). In Saskatchewan, older adults are more likely than younger persons to live in rural areas (Kosteniuk et al., 2015) as 15.5% of the rural population in Saskatchewan is aged 65+ (Moazzami, 2015).

More than 19,000 Saskatchewan residents live with dementia, and an estimated 60 per cent of those individuals reside in their own homes (Kosteniuk et al., 2015). By 2038, an estimated 25,800 Saskatchewan residents will have dementia, which is expected to cost more than $35.9 billion in health and caregiver costs. Community care is projected to become the dominant mode of dementia care in the province by 2028 (Smetanin et al., 2009). Services and programs targeting persons with dementia and their care partners are mainly concentrated in larger urban communities.

For the one-third of Saskatchewan's population that live in smaller cities and rural communities, people living with dementia and their care partners face systemic barriers to accessing dementia care, including limited finances, education, transportation, and

geographic distance (Jeffery et al., 2013). This points to both the importance of understanding the impact of dementia in rural communities and why Saskatchewan provides an important case study from which broader lessons can be learned.

Why Yorkton & Surrounding Area?

Our collective impact initiative is targeting adults living with dementia over the age of 55, and their care partners, who reside in Yorkton and the surrounding area, roughly the area of the former Sunrise Regional Health Authority. Sixteen thousand people live in Yorkton, but an additional 39,000 people reside in the many small towns, hamlets and rural municipalities in the catchment area. Beyond being in close proximity to SPHERU's University of Regina base, the region has one of the oldest population distributions in the province. In addition, a key partner in the initiative, the Alzheimer's Society of Saskatchewan, has recently opened a Yorkton office.

Launching the Initiative: Creating a Collective

In the first year of the project, we reached out to more than 100 community stakeholders (individuals and organizations) in Yorkton and the surrounding area to develop collaborations and partnerships. Because of the restrictions imposed by the COVID-19 pandemic we had to move our initial and ongoing contact with organizations on-line rather than using a more traditional face-to-face approach of community engagement.

Through a series on-line meetings and webinars we outlined both the goals of the initiative and sought to gauge interest from participants in developing and implementing interventions that SPHERU would fund and assist in evaluating. The goal is to have interventions at all three levels outlined in Figure 1 (broad public information campaigns, organizationally specific programs and direct services to individuals). SPHERU, as the backbone organization, is supported by an external Advisory Committee while a Community Impact Table made up of local community, public sector and civic organizations will support the Collaborating Organizations that agree to deliver interventions.

Through these conversations we have articulated a shared understanding of the problem(s) associated with living with dementia in rural areas, framed appropriate responses, and identified priority areas for interventions. These understandings create a framework for a shared agenda around mutually reinforcing activities that are at the heart of a collective impact approach. As the interventions themselves are launched, a common evaluation framework will be developed to track and assess progress. A number of factors have facilitated our efforts in forming our common agenda. These include:

1. *Strong history of community collaboration:* SPHERU has a 20-year history of community-based research in the province as well as recent collaborations with some of the partner organizations involved here. The organizations from in and around Yorkton share a similar history of inter-agency, cross-sectoral collaboration which aligned easily with this project's approach.

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2. *Support from community leaders:* Community leaders have been supportive of our project including local and provincial elected officials. In addition, the Advisory Committee includes members with lived experience with dementia who have proven to be strong advocates for the initiative.

3. *Social inclusion of older adults with dementia is a priority for the community:* Community stakeholders are aware of the alarming situation of older adults experiencing social isolation and have demonstrated their understanding and willingness to address the issue.

4. *Enabling a continuous dialogue and learning:* Our integrated community engagement strategy has fostered strong relationships and trust, raised awareness among various community members, and facilitated an exchange of ideas and proposals.

In late 2020 two foundational projects were completed. Prior to putting forward ideas for interventions there was a consensus amongst participating stakeholder groups that we needed a needs assessment that would investigate what services and programs were available to area residents with dementia or for their care partners. The assessment, conducted by Parkland Valley Sport, Culture and Recreation, found a reasonable availability of "services and/ or programs that were broadly inclusive of people with a variety of special needs or were age-friendly for seniors" that might meet "some needs of people living with dementia." (Parkland Valley, 2021, p.10). But there were few programs or services identified that were dementia-specific.

The assessment also revealed that many of the existing services had been curtailed, moved online or cancelled due to the COVID-19 pandemic. Further, access to those services that moved on-line was hampered by limited connectivity in the catchment area and discomfort with accessing services on-line (Parkland Valley, 2021). The assessment also confirmed the need for further public awareness about dementia.

The second project, completed by the SPHERU team was a population survey of 404 residents 18 years and older in the project area to assess level of knowledge of, and stigma related to dementia (Jeffery et al., 2021). One of the key findings from the survey is the low level of the public's actual knowledge of dementia compared to their perceived (self-rated) knowledge. It also found that stigma is the main reason identified for reluctance to share a diagnosis of dementia with others; Both of these factors could result in delayed help-seeking and further increase feelings of social isolation. The findings from the survey also confirm the need for greater public awareness and knowledge of dementia. A second survey will be commissioned in year four of the initiative to assess population-level changes in knowledge over time given the presence of the local interventions being developed and implemented.

We expect all funded interventions to roll out by the end of 2021 when the evaluation of those interventions will start simultaneously using a shared measurement protocol co-designed with the Collaborating Organizations.

Potential Policy Implications

Collective Impact has created a significant reform in the approach of governments and foundations to community coalition building and multi-sector collaboration in communities. It is a variant of the older concept of multi-sector collaboration that was mostly applied to government agencies, with specific application to the non-profit community sector. The policy implications we draw from current and past collective impact and other multi-sectoral collaboration projects are categorised into four key themes including: bottom-up community-driven approach, continuous communication and integrated engagement, building trust, and continuous learning.

Bottom-up community-driven approach: One important lesson is that communities and people most affected by the issue need to be meaningfully engaged in driving the collective impact initiative. This approach supports community ownership which can lead to more effective implementation of co-designed interventions/solutions. In a collective impact initiative with a truly bottom-up approach, the Backbone Organization's role is to support community stakeholders' leadership instead of leading the initiative.

Continuous communication and integrated engagement: An effective collective impact initiative encourages diverse and inclusive engagement. To this end, we have focused on bringing together a wide range of community stakeholders and actors to the table, from CEO level cross-sector leaders to persons directly affected by the issue (persons living with dementia and their care partners). By adopting an integrated engagement and communication strategy, diverse groups work together to address the issue and tackle the barriers to change.

Building trust: Our experience in designing, implementing, and evaluating collective impact projects suggests that the sustainability and effectiveness of a collective impact initiative depends strongly on trust, especially when collaboration is voluntary. That trust is built through continuous communication to foster a sense of commonality and reciprocity in win–win partnerships.

Continuous learning: Collective impact is not viewed as a solution, but as a problem-solving process, which requires continuous learning and adaptation in order to be successful. This includes organizational or process learning as well as the collective learning of community members. Performance measurement and evaluation, that should be embedded into the entire collective impact stages, are designed to support organizational or process learning through regular feedback resulting in improvement and adaptation.

Challenges

Collective impact initiatives are not without challenges. The key challenges include: the scale up and spread of interventions, evaluation of collective impact, time for relationship-building, and power dynamics.

Scale and spread: One of the major challenges we envision is the ability to scale-up and spread multi-level interventions and transfer them to different community contexts. To mitigate this challenge, we have adopted a realist evaluation that addresses questions of

what mechanisms work, for whom, and under what conditions and contexts. Realist evaluation is concerned not just with the outcomes of interventions but also with the process, context, and mechanisms by (-in) which these interventions are planned, developed, and implemented. This should inform how some of these interventions could be scaled up and spread to other rural communities in Saskatchewan and beyond.

Evaluation of collective impact: Evaluation of collective impact as a whole, not merely evaluation of single interventions, remains a challenge. While the literature on evaluation of single interventions is abundant, evaluation of multiple interventions run by diverse organizations and stakeholders within a collective remains scarce. We know little about how shared measurement differs from measuring outcomes of specific interventions within a collective impact project. We are conducting a scoping review to explore global literature on diverse evaluation methods, frameworks and techniques to examine the evidence on their success.

Time for trust and relationship building: System change is about change in the relationships of people who shape those systems. This highlights the importance of relationships that become both the means and the ends. Building relationships and trust takes a significant amount of time and resources.

Power dynamic: A common challenge to collective impact is unequal power relationships and vested interests among community partners. According to collective action theory in multi-sectoral collaboration (Olson, 1968) each stakeholder does not voluntarily act to advance group interests unless they see benefits and are offered an incentive. In our project, to mitigate power dynamics and prevent domination by a particular community partner, each meeting is facilitated to give all community partners equal voice. In co-designing our common agenda, we have ensured that all community members can clearly see areas of co-benefits and how each partner can benefit from the collaboration.

▶ Conclusion

In the final analysis, much will depend on the outcome of the evaluation(s) that will be conducted as part of the collective impact process. Each intervention will be evaluated by the Collaborating Partner delivering it. The initiative itself will be evaluated by SPHERU and that will include similarly measured outcomes from across the interventions. The advantage with this approach of course is that evaluation is 'baked-into' the very process of doing collective impact initiatives rather than being an add-on or post-hoc undertaking.

More important, perhaps, is how much we can expect to move the needle in increasing social inclusion for people with dementia in one part of rural Saskatchewan with this initiative. If we think about this in terms of the different levels of the interventions (community, organizational and personal) then it is likely the answer is different at each level. Small to modest changes at the community and organizational level, combined with larger changes at the individual level (actually having direct services where few existed before) could combine to move the needle more than might be first expected. In our view, that would count as a win.

▶ References

Please review the online publication for figures, references and more.

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