

Dementia Friendly Life Enrichment Program: Evaluation Report

SaskAbilities (Yorkton)

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Glossary

Term	Definition
Collaborating Organizations	Collaborating organizations are diverse stakeholders from different sectors and organizations who come together in a structured and coordinated way to collectively address complex social issues, pooling their resources and expertise to achieve common goals and create lasting positive change for their community.
Collective Impact	Collective impact is a structured approach to collaboration involving different stakeholders working together to address complex social issues.
Dementia	Dementia is a progressive and degenerative neurocognitive health issue characterized by a decline in cognitive functions including memory, language, reasoning, and the ability to perform daily activities.

List of Acronyms

Term	Definition
DSRS	Dementia Supports in Rural Saskatchewan
PLWD	Person(s) Living with Dementia
SIGN	Society for the Involvement of Good Neighbours
SPHERU	Saskatchewan Population Health and Evaluation Research Unit

Executive Summary

Background

This report provides an assessment of the SaskAbilities Dementia Friendly Life Enrichment Program, supported by the Dementia Supports in Rural Saskatchewan (DSRS) initiative. DSRS is a five-year (2019-2024) Collective Impact initiative undertaken by the Saskatchewan Population Health and Evaluation Research Unit (SPHERU), University of Regina, and funded in part by the Government of Canada's New Horizons for Seniors Program. The Dementia Supports in Rural Saskatchewan project seeks to improve public awareness of the stigma and social isolation experienced by people living with dementia (PLWD) and their care partners. Through DSRS, SPHERU has supported eight collaborating organizations, including the Dementia Friendly Life Enrichment Program led by SaskAbilities, Yorkton. The initiative aims to improve the feelings of social inclusion of persons with dementia and their care partners residing in Yorkton and surrounding rural areas. Specific objectives of the program were to enrich the quality of life of families with lived experience of dementia, reduce care partners' burnout, and connect families to existing supports.

A team of two Dementia Friendly Facilitators and a Dementia Friendly Coordinator use a person-centered plan to engage PLWD and their care partners to plan individual activities of interest that take place at home or in the community. Following these plans, the facilitators engage persons living with dementia in bi-weekly activities including playing cards, lunch outings, or attending/watching sporting events while caregivers use that time for leisure or to run errands. The Dementia Friendly Life Enrichment Program team also plans monthly group outings including lunches, bowling, and education sessions where persons living with dementia and their care partners make new connections with other families with lived experience. The team also collaborates with community organizations to connect families to support including Day Wellness centers, respite services, and other dementia-friendly programs.

Evaluation

The research team at SPHERU conducted an outcome evaluation of the Dementia Friendly Life Enrichment Program to assess the progress on the objectives and outcomes of the project. The evaluation process involved analysis of data collected through document reviews, community visits, and interviews conducted with families with lived experience, local collaborators, and program facilitators in June and July 2023.

Findings

The information analyzed demonstrates that the Dementia Friendly Life Enrichment Program met its three primary objectives of enriching the quality of life of families with lived experience of dementia, reducing care partners' burnout, and connecting families to existing supports.

The first two objectives are interrelated because facilitators carried out activities with persons living with dementia while indirectly providing respite for the care partners. They engaged over 31 persons living with dementia in approximately 900 home and outdoor sessions (visits to provincial parks and museums, canoeing, nature trail walks, picnics, lunches, and group events). These home and recreational activities represent over 1,586 hours of direct support to 62 individuals (31 PLWD and 31 care partners). Care partners received approximately 1,234 hours of indirect respite because, for every support provided to the person living with dementia, the care partner was able to have time for themselves for other tasks. Through the program, families are connected to various services including medical social workers, home care, counselling, and other Dementia Supports in Rural Saskatchewan projects in the area.

We evaluated the impact of the SaskAbilities Dementia Friendly Life Enrichment Program by assessing the key performance indicators for the short-term, intermediate, and long-term outcomes. The program interventions led to increased demand for services from families. The facilitators covered extensive distances — over **52,244 km** — and invested over 1,200 hours into providing direct services and facilitating access to various supports for families. The Saskatchewan Health Authority Medical Social Work departments collaborated and referred families to the program. The individual and group activities contributed to an increased sense of purpose for persons living with dementia and built their confidence as they engaged with other

persons beyond the immediate family. The respite and assistance with navigating other community supports enabled care partners to pay attention to their own health and strengthened their resolve to keep their loved ones at home longer. Though opportunities exist to mobilize community resources to continue the program's interventions, committed funds are indispensable for sustaining supports that are most beneficial to families with lived experience.

The major challenges encountered during this program result from the limited dementia care programming in health and social services in smaller and rural communities. With few supports in place, the team managed increasing demand for services from families while also providing services out of the program's scope including facilitating access to home care and seamless transitions to long-term care.

Key recommendations centered on improving supports to bridge some of the gaps in dementia care within the health system. Participants recommended that components of the programs be integrated into existing supports including adult Day Wellness programs, home care, and long-term care that provide services for older adults including those living with dementia. More training on dementia is required for primary healthcare providers to enhance the use of person-centered approaches in dementia care. It is essential for dementia intervention programs to provide primary healthcare institutions with updated information about existing dementia supports in communities because healthcare providers remain the point of contact for families after diagnosis.



Introduction

Saskatchewan has approximately 1.2 million residents, with about 33% living in rural areas. In 2020, the province also had approximately 17,500 individuals living with dementia with this projected to increase to 42,300 by 2050 (Alzheimer Society of Canada, 2022). It is projected that 62% of Canadians with dementia will be living in their own homes (Alzheimer Society of Canada, 2010).

Older Adults residing in small cities and rural areas often face unique barriers to accessing dementia care and services, including accessible facilities. The absence of sufficient services supporting persons living with dementia in rural Saskatchewan may decrease social inclusion and affect the well-being of older adults with dementia and their care partners. Dementia Supports in Rural Saskatchewan (DSRS) is a five-year collective impact initiative undertaken by the Saskatchewan Population Health Evaluation and Research Unit (SPHERU) and funded in part by the Government of Canada's New Horizons for Seniors Program. The project focuses on improving the public's awareness of the stigma and social isolation experienced by persons living with dementia and their care partners. SPHERU collaborates with provincial and local organizations to design and implement individual, community, and organizational level interventions that enhance the social inclusion of older adults with dementia living in small towns and rural communities in Saskatchewan.

The project aimed to achieve the following objectives:

1. To improve the feeling of social inclusion of older adults with dementia and their care partners residing in Yorkton and surrounding rural areas (individual programs)
2. To improve public awareness about dementia (community programs)
3. To reduce the level of public stigma about dementia (community programs)
4. To improve support for customers, clients, and employees who are living with dementia or their care partners residing in Yorkton and surrounding areas (organizational programs)

The DSRS has funded eight collaborating organizations to design and deliver interventions to address these objectives The SaskAbilities Dementia Friendly Life Enrichment Program

The SaskAbilities Dementia Friendly Life Enrichment Program is one of the projects supported by the DSRS collective impact initiative. The program objectives are to:

- Enrich the quality of life of PLWD by facilitating individualized life enrichment activities in people's homes and in their community
- Reduce care partners' burnout by providing indirect respite to them with the intent of increasing the amount of time PLWD can remain in their family home
- Connect and make referrals to community organizations that may increase natural support in their community

Project Activities

Two Dementia Friendly Facilitators work under the supervision of a Dementia Friendly Coordinator to manage program activities. "*Dementia-friendly team*" is used in subsequent sections of this report to refer to both Dementia Friendly Facilitators and the Dementia Friendly Coordinator. Before commencing the project, the team ran local adverts and collaborated with community agencies including the Alzheimer's Society of Saskatchewan to generate interest and referrals into the program. The facilitators routinely shared the program's Resource Guide and used a person-centered plan to engage project participants – including both persons living with dementia and their care partners – to gauge interest and suitability for the program. They also incorporated input from the participants to coordinate and facilitate outings (recreational and leisure) in the community. These person-centered plans are updated approximately every three months to ensure goals are being met and activities are completed for every individual. Some activities include coffee and lunch outings, walks, lawn bowling, swimming, attending concerts, playing cards, shopping, and attending/watching sporting events.

Creating a weekly, bi-weekly, or monthly schedule with the participating families enables the care partners to schedule time for errands and other appointments. In some cases, the facilitator remains in the home for activities with the person living with dementia while the care partner runs errands; in other situations, the facilitator takes the person living with dementia for an outing, which enables the caregiver to have a break or engage in leisure activities. Over the

course of the project, facilitators have built trusting relationships with the care partners who feel comfortable and confident leaving their loved ones in their care.

The Dementia-friendly team also coordinated monthly group outings for participants and their care partners. These include lunches, bowling, and educational events. The group events take place monthly in different communities, which enables people living with dementia and care partners to make new connections and find a space where they feel supported. The facilitators also collaborate with community organizations/ groups to assist in connecting participants to natural supports as well as bridging the gap for families to access Day Wellness Centres and dementia-friendly support groups.

Evaluation

The SPHERU team is conducting two distinct types of evaluation during the collective impact initiative. The **process** evaluation examines the socio-cultural, organizational, and external factors that have shaped and influenced the design and implementation of the DSRS collective impact project in Yorkton and surrounding rural areas. The **outcome** evaluation examines the short-term, intermediate, and long-term impact of single CO projects. This report presents the findings of the **outcome evaluation** for the SaskAbilities Dementia Friendly Life Enrichment Program.

Methods

The outcome evaluation, conducted between June and July 2023, was designed to assess the short-term, intermediate, and long-term outcomes of the project. We collected data through semi-structured interviews, document reviews, and observations through community visits. We conducted 11 semi-structured interviews with persons living with dementia, care partners, Dementia Friendly Facilitators, and the Dementia Friendly Coordinator. Documents reviewed included regular meeting records, bi-annual program completion reports, and stories of change drawn from participants on an ongoing basis. We examined the key performance indicators that reflected the achievement of short-term, intermediate, and long-term outcomes. The subsequent sections present key findings from the evaluation related to progress made in achieving the project's objectives and outcomes.

Findings

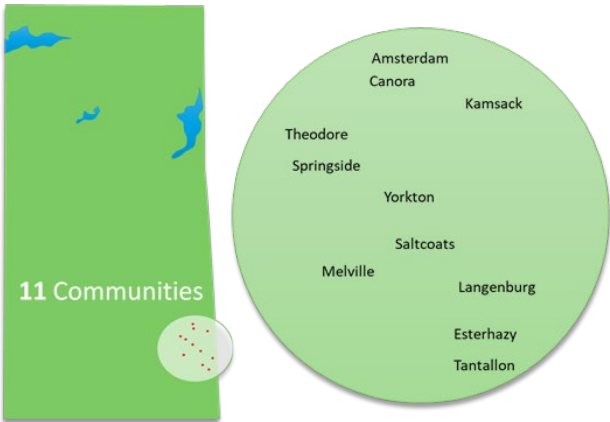
Project Objectives

The information analyzed reveals that the Dementia Friendly Life Enrichment Program met its three primary objectives.

Objectives 1 and 2: Life Enrichment and Respite

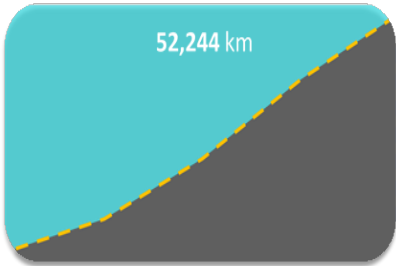
The first objective of the Dementia Friendly Life Enrichment Program is to enrich the quality of life of people living with dementia through life enrichment activities while the second objective aims to reduce care partners' burnout with the intent of increasing the amount of time persons living with dementia can remain in their home. These two objectives are interconnected because the facilitators engaged persons living with dementia in activities while indirectly providing respite for the care partners. The following summary reflects data collected about activities and respite provided from April 2021 to October 2023.

Figure 1: Communities Reached



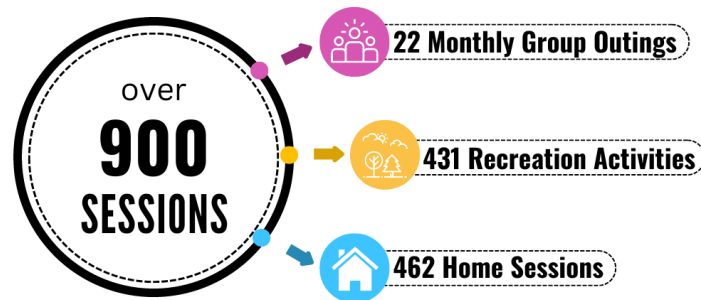
From April 2021 to September 2023, the dementia-friendly team travelled **52,244 kilometres**.

Figure 2: Distance Travelled



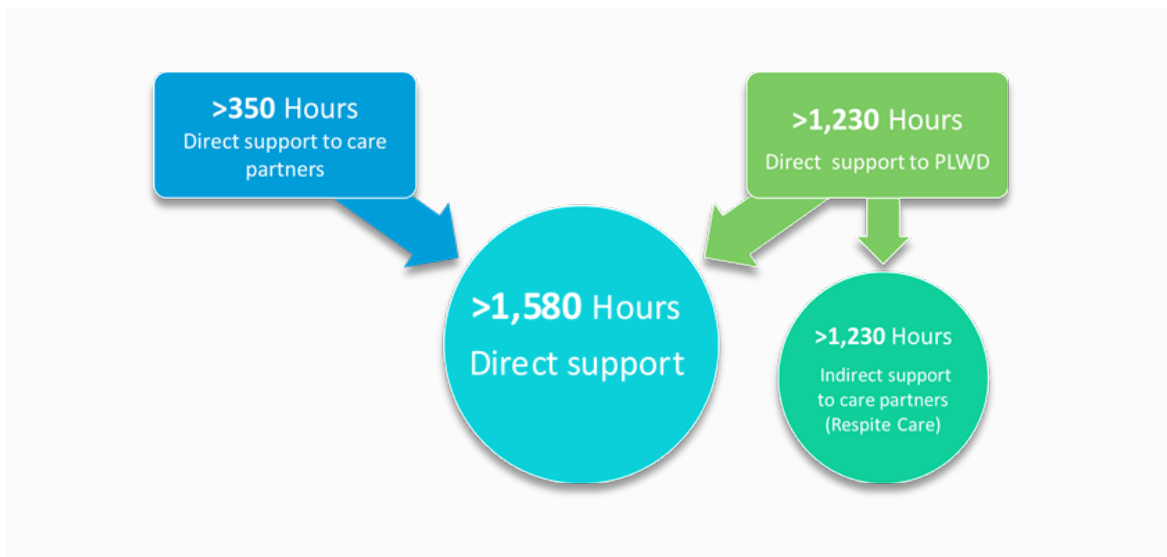
From April 2021 to September 2023, the dementia-friendly team travelled **52,244 kilometres**.

Figure 3: Sessions



Over approximately **900 sessions**, facilitators provided **1,586 hours of direct support** to **62 participants** (31 PLWD and 31 care partners). During **472 home sessions**, facilitators engaged persons living with dementia in crafts (including making wooden trucks, centerpieces, wreaths, birdhouses, bird feeders, and painting) and playing board games. Facilitators engaged persons living with dementia in **289 recreational activities** including visits to the provincial parks and museums, canoeing, nature trail walks, picnics, lunches, hockey games, and drives to various locations determined by the family.

Figure 4: Hours of Support



The average support time for each person living with dementia increased from approximately 6 hours during the first six months to approximately 29 hours from April 2023 to September 2023. Though participants with advanced stages of dementia generally preferred to stay at home, the

desire to be active in the community is reflected in the increasing number of recreation activities requested in person-centered plans and the distance travelled by facilitators and persons living with dementia. Some factors contributed to this upsurge in activities beyond the home. Firstly, as facilitators built relationships with the families, families developed trust, and care partners were more comfortable leaving their loved ones in the care of the facilitators. Secondly, once COVID-19 restrictions were lifted, families felt more comfortable leaving their homes. Thirdly, facilitators were able to allocate more time for visits when participant numbers dropped, for instance when some persons living with dementia transitioned to long-term care or passed away. In a few cases, facilitators assisted care partners with transitioning their loved ones to long-term care and continued to visit the person living with dementia. The support provided during this period supported the families to adjust to their new circumstances

Facilitators provided over **350 hours of direct support** to care partners, including joint outings and group events with facilitators as well as support provided over the phone by facilitators. By October 2023, care partners in the program had received approximately **1,234 hours of respite**. For every support provided to the person living with dementia, the care partners had time for themselves or engaged in other activities including having coffee with friends or catching up with a doctor's appointment. It would have been challenging for the care partners to perform several tasks without the additional support provided by the facilitators

Objective 3: Connecting Families to Supports

The third objective of the Dementia Friendly Life Enrichment Program is to connect and provide referrals to community organizations that may increase available support for families within their communities. Over the project period, the dementia-friendly team connected families to various services including medical social workers, home care, counselling, peer groups, helplines, and the Alzheimer's Society First Link Coordinator. They shared resources with families about ongoing programs of interest; furthermore, some participants chose to explore these programs, including four other Dementia Supports in Rural Saskatchewan projects being implemented in the area (Belong where You Find Yourself, RaDAR Memory Clinics, the Cognitive Kitchen, and Alzheimer Society in Saskatchewan's Public Awareness Campaign).

Project Outcomes

We evaluated the impact of the Dementia Friendly Life Enrichment Program using the key performance indicators (KPIs) (see Appendix A), which were co-developed with the Dementia Friendly Life Enrichment Program team and constantly reviewed during the planning and implementation phases of the project. We assessed the extent to which project activities matched the indicators for the short-term (reach and engagement), intermediate (effectiveness), and long-term (sustainability and transferability) outcomes.

Short-Term Outcomes: Reach and Engagement

Regarding reach, the data indicated that the Dementia Friendly Life Enrichment Program facilitators and a coordinator covered extensive distances and invested over 1,200 hours to provide services and connect families to various supports available within their communities. As word spread about the projects, community collaborators including the Saskatchewan Health Authority Medical Social Work department in Yorkton, home care assessors, nurse practitioners, and other Dementia Supports in Rural Saskatchewan collaborating organizations in the area (Alzheimer Society of Saskatchewan and the Godfrey Dean Art Gallery) continually referred families to the program. Over 60% of the participants were referred to the program by these collaborators.

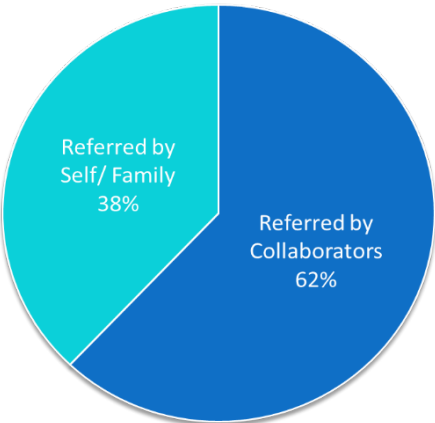


Figure 5: Referrals to the program

Individual inquiries about the program also increased as family members who heard about the program via word of mouth and local adverts inquired about the program for their loved ones.

As of September 2023,¹ there were over 16 individual family inquiries about the program. While some of the inquiries led to participation in the program, other families chose to wait until their person living with dementia was ready to be part of the program. The program's activities resulted in a growing interest in the program and awareness about the gaps in support for families with persons living with dementia, especially in rural areas.

Intermediate Outcomes: Effectiveness

For the purpose of this project, effectiveness as an outcome refers to the impact of the intervention on the well-being of families with lived experience of dementia. We examined how the Dementia Friendly Life Enrichment Program activities contributed to increased quality of life, feelings of social inclusion, care partners' coping abilities, knowledge on accessing supports, and the length of time PLWD remained in their homes.

Quality of life

Overall, the observations about the program were positive as persons living with dementia, care partners, and program facilitators shared that the direct service provided to individual families and the community outings had increased their sense of value and feelings of inclusion.

For persons living with dementia, the program provided opportunities to engage in activities they enjoyed because the team adopted a person-centered approach, planning activities based on the interests of the person living with dementia. As they participated in these activities, it improved their sense of purpose and value as community members. Feedback from interviews indicated that – since persons living with dementia were familiar with the planned activities – it gave them something to look forward to, which boosted their sense of purpose and belonging in their communities.

¹ This report covers the start of the Dementia Friendly Life Enrichment Program from April 2021 to September 2023. Project activities were still ongoing at the time the report was written because the project was extended to end in June 2024.

"I like going for coffee at McDonalds, it seems to be something that I feel comfortable doing. I enjoyed going bowling; I'm slowly starting to catch on to throwing the ball correctly." PLWD 04



"...it's not only helping them socially, it's helping them cognitively. Because there's reminiscing...you're doing purposeful things. It gets them out, it gets them walking, it gets them talking, it gets them bowling. He's doing physical, and you're touching all five basics of health, right? You're getting all of them, which are all very important for your whole well-being" Care Partner 04



"... it just gives them something to look forward to, and I think they have that little spark in them...I think that if they have something to look forward to, it kind of keeps them going a little bit more. Instead of just, you know, if they're just sitting at home and looking at the TV, or just by themselves... It's not much, the same thing over and over again, and that kind of brings a person kind of down, you know?" Facilitator 03



"By virtue of having their own activity, it gives them their own identity. And their identity isn't a person living with dementia, their identity is 'Joe Brown,' and he likes to go curling, or he likes to go, or, you know, likes to go for lunch..." Community Collaborator, Yorkton

In the words of another interviewee, participating in familiar activities when they would have otherwise not had the opportunity, the person living with dementia had *"a chance to tell their story and takes them back to when they were strong."* Some people living with dementia,

supported by facilitators, now enjoy leisure outings without their care partners. One of the dementia-friendly facilitators observed that a person living with dementia began to *“all of a sudden feel like, I can do this, you know? I can go out. I don't have to have my husband holding my hand and helping me walk and stuff”* (Facilitator 01).

Beyond the sense of achievement that persons living with dementia expressed after having engaged in certain activities, facilitators and some care partners mentioned that they had witnessed an increase in the person living with dementia's mood, recall, and social interactions at home after returning from outings.

“I have noticed that he is able to provide more information about topics he talks about. He [PLWD] has noticed that his speech has improved since he has started visiting with [Facilitator]. He [PLWD] has asked if [Facilitator] would be able to work in Regina when they move there” Care Partner 06

For care partners, the program improved their quality of life because it contributed significantly to reducing burnout. While the facilitators engaged with their loved ones, they often used the time to run errands, attend medical appointments, visit the salon, or have coffee with friends. They also noted that an added advantage of the program is the relationships that facilitators have cultivated with families. Program participants found that persons living with dementia and care partners bonded with and trusted the facilitators, which made it possible for the caregivers to maximize their time to themselves instead of worrying about the person living with dementia. They appreciated the well-needed breaks and had peace of mind because they knew their loved ones were safe and having fun.

“... it gave me a break to do what I needed to do. Say go for a haircut, or, you know, to grocery shop by myself, actually. And things like that, or if I had a doctor's appointment, I could schedule it when I knew [Facilitator] was going to be here...” Care Partner 05



“Well it gives us both a break from each other...Her situation isn't as advanced yet as lots of patients, but still can't be left alone.

We're basically joined at the hip ... we literally have to do everything together. Which is okay. But just that little bit of time, you know, away from each other or with someone else is very refreshing and relaxing and rejuvenating. Gives you just a little bit of a break to recharge your batteries again, keep going” Care

Partner 01



“But it's just, it's so nice to have [PLWD] go with [Facilitator], so that I can have a little bit of time to do things like paying the bills and you know, even having coffee with my friend. Sometimes I get caught up in things and kind of forget ...you know, just that time for myself.” Care Partner 02

Increased interaction and feeling of social inclusion

The Dementia Friendly Life Enrichment program’s individual and group activities enabled persons living with dementia and care partners to engage with other persons beyond the immediate family. For some persons living with dementia, the outings to restaurants, parks, and games presented the opportunity to engage in conversations with other acquaintances beyond the vicinity of the home.

“...there's a fair age between [Facilitator] and I, to be able to, you know, relate to one another the way we do. We went to a hockey game...and we talked, we visited, talked nonstop all through the hockey game... we are 40 years different in age or something like that? And, you know it's just, how can we have so much to talk about?” PLWD 02



“PLWD continues to have confidence and really puts himself out in the community, especially during the last few outings. PLWD went up to a man in the pool hall that he knew and talked to him for some time which is something that the PLWD would have not done in the past...” Facilitator 03

One person living with dementia commented, *“I'd lose my mind fast”* without these engagements and socializing. Some care partners mentioned that their loved ones were always looking forward to the visits because they would go watch games and visit museums. One care partner indicated that her husband couldn't wait to go out, and each Friday he would ask, *“Is this my Friday with the [facilitator]?”* For some persons living with dementia who were at an advanced stage, their care partners expressed that the program engagements were a *“social pillar for their lives”*.

“It's absolutely made a difference for him, he sure looks forward to his outings with [facilitator]. They do lots of, you know, different things that we probably wouldn't have done as a couple. Like, they go bowling and they go, you know, they go for coffee, or they- they'll go to the arcade” Care Partner 03

“... I could see the decline during that time. But I still think the program was very valuable for him and for me to feel, have him feel, that he's still part of something social... I think we were so blessed just to have that social pillar in our lives” Care Partner 05

Regarding caregivers, the group outing activities brought people from surrounding areas together, creating connections with other families. According to participants, this was an added advantage of the program. Unlike in urban areas, it is more challenging to plan leisure “get-together events” in rural areas because of long travel distances. Through these events, participants met families with similar experiences where they shared their experiences without feeling judged.

“Last week, we were in Esterhazy. I don't know if I've ever been to Esterhazy, and it's only a drive away. So, it kind of gets me out into different communities too... I really enjoy the outings...we get to see, like, museums and the different parts of different communities...Something I probably would never do on my own” Care Partner 03



*“...it's such a great outing...it's almost like a relief. Because you know that you're not alone in this. So, that's the part that I really like... programs like this, to me just really help with the isolation part. You can get out and see other people, even if it's for an hour... And I kinda like the part that I know I'm going to the safe place”
Care Partner 02*

The Dementia Friendly Life Enrichment team had originally planned group activities specifically for families in each hometown to reduce travelling for persons living with dementia and care partners. However, the care partners enjoyed the group meetings and were willing to travel to different towns for the outings. These group outings took place in communal spaces and provided opportunities for participants to interact with other people in the community. According to one of the facilitators, these opportunities provided avenues for persons living with dementia and care partners to engage and build their confidence to interact with community members that they encountered.

"...once we get into the groups, and we're going to Manos, or we're going to the lake...they feel like 'this is the program that allows me to be in the community' ... it just builds the confidence and the ability to just talk to whoever it is that they come across, versus shying away" Facilitator 02

Through these group events, care partners have developed relationships whereby they communicate with one another outside of project activities, encourage others in challenging moments, or meet for coffee. Care partners observed that they are able to connect to other care partners, even though their loved ones might have been experiencing different stages of dementia. They indicated that their experiences made it easier to empathize, support, and bond with each other. Facilitators observed that care partners who had lost their loved ones or transitioned to long-term facilities continued to provide support to the other group members.

"...just visiting with them and talking, helps on a day-to-day basis for us, too. Because they'll say, 'Well, you know, with my spouse, or my person I'm giving care to, this happened or that happened.' And you can say, 'Well, gee, that's only happened to us once. But you know, what did you do? So if it starts happening more frequently, what are some of the things you tried so that I can, I can work with that" Care Partner 01

“...with care providers, they really have like a close knit group, and a lot of them talk to each other, even out of the program, they message each other, or phone each other... we even have some of the participants that have passed, and the care providers still come to the groups and still talk to the other care providers.” Facilitator 03

According to some participants, their family members valued this opportunity for their loved ones to feel included in their community.

“They felt comfortable because they knew that we were involved, and that we were doing something other than just sitting at home and watching TV, or just going for a drive somewhere, you know. Because that meant that other people were still involved with our lives” Care partner 05



“...they're aware of the program and how we use it, and I know that they're sure that it's of a great benefit to us. Because without like I say, we're stuck just with each other and TV, and in a small town, it gets pretty repetitious pretty quick.” Care Partner 01

While some participants commented that friends and faith-based groups within their communities had been supportive, many care partners felt that the program’s gatherings were unique and more beneficial because families met others who were on the same dementia journey.

Increased coping ability for care partners

There was a consensus that keeping people living with dementia at home longer in their own familiar environment helps to improve their general well-being, and one of the key factors that influence decisions to keep persons living with dementia at home longer is their caregivers' coping ability. With the support and respite provided by the Dementia Friendly Life Enrichment program, care partners were able to pay attention to their own health. For many participants, reducing the caregiver's risk of burnout and enhancing their ability to take care of their own health has been vital because healthier care partners were better able to care for the person living with dementia for longer, thus increasing time spent at home and postponing the transition to long-term care.

"...they'll come out and tell us, you know, 'I'm this close to putting her into long term care,' or, 'he needs to go to long term care. But I know that I can do it a little bit longer'... And I have one example of the lady that was overwhelmed... She told me if she didn't get help from us, she would have put them into long term care a year or two ago" Facilitator 01

Some care partners who were nervous about taking their loved ones out relied on facilitator support for certain activities including visitation to favourite locations. Care partners felt these supports enhanced their wellbeing and that of their loved ones, which all contribute to keeping their loved ones out of hospitals and nursing homes. This was especially true for more elderly care partners. A participant concurred with this reasoning, remarking that *"every one of them would be in long-term care a lot earlier"* if the supports were not provided.

Navigating existing supports and access to resources

Another factor that influences decisions to keep persons living with dementia at home longer is the ability to maximize existing supports provided in the community. Participants shared that the Dementia Friendly Life Enrichment team had facilitated connection with other supports for people living with dementia including other Dementia Supports in Rural Saskatchewan initiatives in the area. Some caregivers mentioned that the knowledge gained from their peers about managing the constant changes that are characteristic of persons living with dementia strengthened their resolve to keep their loved ones home as long as possible. For instance, a care partner shared that the facilitators had recommended Zoom sessions; during which she had learned about addressing behaviour challenges and crisis moments.

“...there was one on behaviour challenges, you know, how to deescalate instead of escalate a situation. And, you know, maybe that should be common sense for me, but it's not... and there was a fall prevention zoom... I wouldn't have been aware of all these programs, if we hadn't have joined the SaskAbilities program... one connection leads to another and it's all entwined.” Care Partner 02

Care partners struggling with behavioural changes and other dementia symptoms are often called by the Dementia Friendly Coordinator and facilitators to share their challenges. While the team often offered direction and emotional support, they also helped the care partner to adapt by recommending supports to ease caring for a person living with dementia at home.

“...there are people with disabilities out there, and we adapt a lot of things. But the care partners don't always necessarily know those strategies, right? Because that wasn't their line of work...some people just don't know, like there's bath chairs, there's toilet seat lifts, there's lots of different devices that you can use. I had to get a person an alarm for when the person with dementia leaves the room, there's a sound and it wakes the care partner up...” Facilitator 02

Given that rural areas generally have limited resources and services, the dementia-friendly team took on the role of helping caregivers navigate the health system and access services.

“...the coordinator helps the care partner navigate that care system, whether that be through the Alzheimer's Society or home care if that's needed. Like the referrals that need to be sent out, we discuss that and we get them hooked up with people and other services.” Facilitator 02

Connecting participants with various resources reduced the time and effort care partners would have required had they attempted to navigate these services themselves. Caregivers expressed that in the absence of these supports, they would have had to rely mostly on the health system, which is lacking in dementia care. Overall, the persons living with dementia, care partners, facilitators, and other community collaborators described the program's interventions as being effective in improving available support for families with experience of dementia. One of the participants concluded, *“I find there's a big gap between health care and dementia care, and a program like this really goes a long way to help that.”* A collaborator concurred:

“...we do have home care and whatnot throughout the province, but that's so limited... So this program, by being able to go out to the patient and their family is so so valuable...it gives the person living with dementia the opportunity to focus on their own interests...” Collaborator, SaskAbilities Dementia Friendly Life Enrichment Program, Yorkton

Other outcomes: Dementia Friendliness in Business Community

An unintended outcome of the Dementia Friendly Life Enrichment Program is that it helped increase awareness and understanding in the community. While the program's objectives focused mostly on support for persons living with dementia and their care partners, the group activities involved taking persons living with dementia and their care partners to community spaces. Consequently, there is an increased willingness by businesses to make adjustments, accommodate, and create dementia-friendly atmospheres for persons living with dementia and care partners. At least three restaurants have consistently provided quiet and accessible spaces for group lunches for the Dementia Friendly Life Enrichment Program participants.

Long-Term Outcomes: Sustainability and Transferability

The key factors examined under sustainability relate to actions that have been taken and those required to preserve the SaskAbilities Dementia Friendly Life Enrichment Program interventions in Yorkton and surrounding areas. For transferability, we analyzed the indicators that demonstrate the capacity for the program's interventions to be implemented in other contexts. We tracked the levels of community engagement with the program, partnerships with local stakeholders, and the factors that enable sustaining interventions, and adapting components of Dementia Friendly Life Enrichment Program dementia care strategies within existing supports.

Partnerships

The increasing number of referrals received from individuals and local collaborators as well as active participation in activities reflect a sustained interest in the program within all communities served by the project (see Figure 1). The Dementia Friendly Life Enrichment Program collaborates with the Saskatchewan Health Authority Medical Social Work department in Yorkton. Some of the medical social workers travel out to smaller communities around Yorkton and provide referrals from those communities to the Life Enrichment Program. Saskatchewan Health Authority Occupational Therapists also refer families with persons living with dementia to this program. Through this process, the Dementia Friendly Life Enrichment team takes on participants and refers potential participants to other Dementia Supports in Rural Saskatchewan collaborating organizations, home care, and counselling peer groups. A home care assessor has

inquired about providing Dementia Friendly Life Enrichment Program services for those with dementia in long-term care.

Through these connections, the Dementia Friendly Coordinator has trained nursing staff from the Yorkton District Nursing Home on person-centered approaches and building rapport and worked with the Nursing Home Clinic Lead to facilitate services for persons living with dementia displaying complex behaviors.

Funding

Feedback from ongoing evaluation throughout the project indicated that the program requires committed funding to sustain services at minimum levels. For this reason, a key aspect of the Dementia Friendly Life Enrichment Program sustainability plan was to produce a dementia-friendly video that portrays the benefits of the program. A 14-minute video was produced that captures participants' perspectives on how the program has improved their quality of life.

The Dementia Friendly Life Enrichment Program team also organized environmental scans aimed at discussing potential funding opportunities and appraising the support required for developing business case plans for continuing services. Some of the parties involved in this process include directors of primary health, continuing care, acute care, the Alzheimer Society of Saskatchewan, Saskatchewan Senior Mechanism, and the Society for the Involvement of Good Neighbours (SIGN). The environmental scans indicated that there is support for the Dementia Friendly Life Enrichment Programs and it is not a duplication of services, as it is the only program that offers direct service provision. As part of the sustainability plan, SaskAbilities successfully applied to and were awarded funds through the following grants: Healthcare Excellence (Aging in Place), Saskatchewan Seniors Mechanism (Facilitating Independence Grants Support to age well at Home), Government of Canada (New Horizons for Seniors Program). While these grants will assist in the sustainability of the program, collectively they will not cover the salaries required to maintain the current staff ratio. To address long-term funding, the SaskAbilities Management team has prepared a Request for Funding that will be presented to the Ministry of Health; Ministry of Mental Health and Addition, Seniors and Rural and Remote Health in April 2024.

Leveraging donations and volunteers

The Dementia Supports in Rural Saskatchewan funding for projects ends in June 2024. Therefore, there are ongoing discussions about fundraising to continue. At a community level, some families that benefited from the program have raised the possibility of sustaining some aspects of the program through donations.

“I'm sure there's businesses and people in the community who would volunteer both time and capital, and maybe other resources... would there be capital out there that would be available? I think so. Would there be enough to make the program run? I have no idea...but yeah, I think given an understanding of what's required and then what's necessary, I think on a community basis we could raise some help...” Care Partner 01



*“I would definitely hit up the Saskatchewan Health Foundation... The Alzheimer Society, and adults in the Society should also be funding this...they're the ones who do a lot of fundraising... if the Alzheimer's Society supports this program that would be something I would actually donate more money to...”
Care Partner 04*

Although there is optimism that avenues exist to mobilize resources from within the community to continue certain supports, some participants observed that committed funds are indispensable for continuing key aspects of the program most needed by families with lived experience of dementia.

“...people have asked if we would accept donations from individuals to help us keep the program going. The only thing is, the people that are asking that don't realize how much this program costs... They don't realize how much the program costs because they only see a small portion of it, right? They don't see me going out to 10 different homes. They only see me coming to theirs” Facilitator 01

Regarding volunteering, there was less enthusiasm for other community members providing similar dementia care interventions that are similar to the Dementia Friendly Life Enrichment Program. Many participants were of the opinion that the complexities involved with coordinating and implementing projects that work with volunteers may challenge the effectiveness of the program. Firstly, they attributed the success of this program to the fact that the facilitators are knowledgeable and trustworthy, hence their ability to reduce the burden on families. Conversely, volunteers would require training, may not have insurance, or may require staff supervision to perform certain tasks with persons living with dementia (i.e., transporting participants to certain locations).

Secondly, they observed that there is limited accountability when people volunteer and thus reliability might be a challenge. This is especially important in terms of dementia support because caregivers would be reluctant to entrust their loved ones into the care of another if they cannot rely on their services. Some participants also reasoned that there might be few people within the community who would be available to volunteer. For example, though immediate family members generally provided support, some persons living with dementia had no surviving family members or any who lived close by. In some cases, adult children were busy managing young families and jobs, leaving the care partner to bear most of the responsibilities.

Generally, there was a consensus that committed funding is vital for incorporating the program's strategies within services that provide dementia care. For example, the new partnerships and connections developed with other services demonstrate the possibilities of leveraging

community networks to bridge gaps in dementia care. Nonetheless, interviewees were of the opinion that the interventions that improved the quality of life for families require a dementia care strategy; one that supports and expands dementia care services including those provided by the Dementia Friendly Life Enrichment Program.

Regarding transferability, the use of person-centered plans emerged as a key practice of the program that is feasible for implementation in institutions providing care for community members living with dementia. Facilitators used these plans to help families determine activities of interest that improve the quality of life for the person living with dementia. Over 30 person-centered plans were developed and constantly reviewed during the course of the project. The facilitators shared that the use of person-centered plans is flexible and highly adaptable, and thus suitable for training staff providing respite through Day Wellness, home care, or other similar programs in rural communities.

The SaskAbilities Dementia Friendly Life Enrichment Program team continues to implement its sustainability plan including collaborating with stakeholders to highlight both the benefits of the interventions for dementia care in rural areas and the need for secure committed support for Dementia Friendly Life Enrichment Program beyond June 2024.

Challenges

Three key challenges emerged during the implementation and delivery of this program.

COVID-19 pandemic & stigma towards dementia

Firstly, the initial stages of the Dementia Friendly Life Enrichment Program commenced during the COVID-19 pandemic. Consequently, families with older adults were reluctant to enroll and participate in some of the activities during the early phases of the program. *Secondly*, some families were hesitant to join the program due to stigma. Some loved ones were in denial of the diagnosis or did not want their situation known by others; therefore, there was limited interest in the Dementia Friendly Life Enrichment Program activities. However, as the COVID-19 pandemic

risks reduced and more people became familiar with the program and its benefits, families were willing to explore the support provided.

Limited dementia-friendly services in long-term care

The *third* and key challenge regarded the gaps created by limited support in health and social services in smaller and rural towns. Most of the challenges encountered point to the gaps between healthcare and dementia care. Primarily, there are few appropriate resources and programming within existing supports including long-term care homes. When participants in the program transition to care homes, they tend to require more support, and the Dementia Friendly Life Enrichment Program team has had to fill this gap. For instance, one person living with dementia transitioned into long-term care and did not have a caregiver or family in the area. The long-term care facility requested that the Dementia Friendly Life Enrichment Program continue to support this person living with dementia, as the nursing staff struggled to support and build rapport with the person. Additionally, the programming in long-term care is not suitable for persons living with dementia who make the transition during their active stages. They struggle to adapt to life in the care home, as they are not able to participate in activities that meet their individual interests, such as going to hockey games and other recreational activities. Participants reasoned that these gaps in long-term care homes could trigger health decline in persons living with dementia.

Limited resources to facilitate access to existing supports

Another challenge linked to the dearth of services is that there are no resources to facilitate care partners' access to existing supports. They often must fend for themselves regarding processes of accessing home care, transitioning to long-term care, and other supports that are required for a seamless transition for persons living with dementia and care partners. While the facilitators have the training and skill sets to provide different types of support to clients, facilitators often take responsibility for supports that ought to be delivered by other services. For instance, medical social workers are assigned to help persons with intellectual disabilities; however, there are no similar services reserved for older adults living with dementia, especially those with no family. In

the absence of these supports, some seniors with dementia and care partners struggle with accessing certain services. Facilitators shared examples of such scenarios:

“...we have one guy, the guy that transitioned to the nursing home, no family members. He moved to the nursing home in February. We still have no access to his funding, because he has no public trustee. So where is his money going? ... good that our program pays for everything, but like, the guy can't even buy himself snacks to the nursing home because no one knows who his public trustee is...” Facilitator 02



“...I had one lady that was it was overwhelming to her... I more or less became the person that she'd go to, to ask for, 'where do I go now?' Like, 'what do I do now? ... And literally, I had to lay out a plan for her to be able to get everything in order. Because they- their finances weren't in order...she knew that her husband wasn't going to be home very long. So there was a lot of things that she had to get. A lot of legal things and things...she had no clue how to do it...” Facilitator 01

With few supports in place, the Dementia Friendly Life Enrichment Program team had to manage increasing waitlists and requests from clients for more hours while also providing support that was not within the program’s scope. This requires that the Dementia Friendly Life Enrichment Program invest resources into work that could be picked up by other community and government services.

Recommendations

Recommendation 1: Planning for Inclusive Services

There is a need to develop services that are inclusive of persons living with dementia. Participants highlighted that empathy is required at different levels of decision-making to develop, implement, and support dementia care, especially in rural areas. Components of the Dementia Friendly Life Enrichment Program should be integrated into social services and long-term care to support those older adults living with dementia who have no family.

Recommendation 2: Practical Adjustments to Existing Supports

Home care could upgrade its services to include the provision of nutritious meals and monitoring medication intake where needed. Facilitators observed that some care partners were not keen on cooking or were overwhelmed with providing care and other household tasks; thus, they were more likely to rely on frozen and microwaved meals for themselves and the person living with dementia. They recommended that home care staff could fill another gap by adding reminders to their routine to ensure that the person living with dementia are taking medications consistently.

Home care assessments should start earlier for older adults living with dementia so that in the event of the loss of a care partner the relevant services would be aware of the person living with dementia's situation and provide appropriate support.

Participants recommended that components of the Dementia Friendly Life Enrichment Program could be an integral part of home care services, especially given the gap in dementia care within the health system.

Recommendation 3: Expand the Program to Other Areas in Saskatchewan

There is a need for appropriate community-based programs for persons living with dementia and their caregivers. The program could serve as a pilot case to inspire a provincial dementia care strategy for implementation in rural communities throughout the province, especially those without adult Day Wellness programs or caregiver support groups. Future programs that aim to

improve dementia care could utilize satellite locations in rural communities to reduce the time spent by staff travelling to provide support.

Recommendation 4: Leverage Primary Health Care to Share Information on Existing Supports

Some participants observed that – in certain cases – primary healthcare providers are not adequately informed to provide the next steps after a dementia diagnosis. It is essential for dementia intervention programs to provide doctors’ offices with updated information about organizations providing dementia-related services in the region. These updates could be brochures displayed or handed out at primary healthcare institutions because healthcare providers are the point of contact after a dementia diagnosis and act as major stakeholders for health information dissemination.

“The older people, they don't go out and search, they don't do this kind of stuff. So, you know, your doctor should be able to say, 'well, you know, I'm gonna give you a number,' or even, 'I can call this number for you and get you attached to this program or that program.' Well, that's not happening, you know? It's not happening. So, like, you're almost like, telling the doctors what's happening out there. And I get that they're busy, but I mean, you want them to have a little bit knowledge about the disease, too” Care Partner 03

Recommendation 5: Dementia Awareness Training for Healthcare Staff

More training on dementia is required for primary healthcare providers who deal directly with persons living with dementia. Gaps were observed in long-term care homes where staff struggled with a person living with dementia who transitioned from the Dementia Friendly Life Enrichment Program to the care home. A care partner shared that a health professional was surprised that the person living with dementia needed help and directions for undressing before a doctor’s

examination. According to this participant, she expected that a doctor would expect some challenges that are common with some stages of dementia. Participants explained that increased awareness amongst healthcare providers could promote changes in attitudes and equip staff to utilize person-centered approaches in dementia care.

Conclusion

Overall, participants were satisfied with the program because it enriched the quality of life, reduced burnout for care partners, and connected families with lived experience of dementia to existing supports. However, it is apparent that sustaining these key aspects of the program is hinged upon the ability to secure funding. Though avenues exist to mobilize resources from within the community to continue certain supports, committed funds are crucial for continuing the main activities of the program most needed and appreciated by families with lived experience of dementia in these areas. As such, SaskAbilities continues to explore opportunities to secure funding to sustain the Dementia Life Enrichment Program after the Dementia Supports in Rural Saskatchewan Project funds end in June 2024. The key recommendations from the program highlight the need for appropriate community-based programs for persons living with dementia and their caregivers in rural communities. Moreover, a robust plan and continuous effort is required to bridge gaps within the health system to establish a provincial dementia care strategy for implementation in rural communities throughout the province. Beyond securing funding, broad community support is essential and possible through continued awareness that equips people to effectively communicate and interact with persons living with dementia in various settings including grocery shops and kayak clubs.

References

- Alzheimer Society of Canada (2022). *Navigating the path forward for Canada: The landmark study*. Toronto, Ontario.
- Alzheimer Society of Canada (2010). *Rising tide: The impact of dementia on Canadian Society*. Toronto, Ontario.

Appendix A: SaskAbilities Dementia Friendly Life Enrichment Program Key Performance Indicators (KPIs)

KPIs to Measure Short-Term Outcomes

Reach: Number of the target population who access the intervention/program.

Engagement (use or participation, acceptability, or uptake): Level of population interactions with the intervention/program or the content of intervention/program such as feedback and comments received.

KPIs to Measure Intermediate Outcomes

Effectiveness (or usefulness): Impact of intervention/program on knowledge (e.g. enhancing public awareness), behaviour (e.g. reducing stigma), and practice (e.g. improving supports for customers and clients).

Unintended Outcomes (positive or negative):

Positive Outcomes: Positive impact on care providers by providing support to persons living with dementia; better relationship with other family members and neighbours in the community

Negative Outcomes: Care partners not willing to give up any support for clients (detaching co-dependency of care partners and establishing better independence for clients); care partners' feeling guilty; inappropriate referral (e.g. not being able to provide services to those in crisis or those with high needs who don't meet criteria depending on the stage of disease)

KPIs to Measure Long-Term Outcomes

Sustainability: Degree to which the intervention/program is continuously used, normalized, and incorporated/integrated into public behaviour and/or organizations activities (institutionalized)....

Transferability: Extent to which the intervention/program could be effectively implemented in another setting/context. ...

List of Abbreviations:

- **PLWD:** Person Living with Dementia
- **DFF:** Dementia Friendly Facilitator
- **EC:** Evaluation Coordinator
- **CO:** Collaborating Organization
- **CP:** Care Partners

Activity: Dementia Friendly Life Enrichment Program

Activity Objective:

- 1) To enrich the quality of life of PLWD by facilitating individualized life enrichment activities in people's homes and in their community
- 2) To reduce care partners' burnout by providing indirect respite to them with the intent of increasing the amount of time PLWD can remain in their family home
- 3) To connect and make referrals to community organizations that may increase natural supports in their community

Collective Impact Project Objectives to Achieve:

To improve the feeling of social inclusion of persons with dementia and their care partners residing in Yorkton and surrounding rural areas.

Outcome Measures		Indicators	Data Collection Method
Short-Term Outcomes	Reach	1) # and name of referral sources developed (i.e. self-referral and referrals by agencies including project partners and collaborating organizations who refer clients to the program)	Tracking
		2) # of referrals from various sources	Tracking
		3) Distance travelled and the time travelled	Tracking
		4) Types of activities provided by the program (playing games, playing music, art, and shopping)?	Tracking
	Engagement	1) # of PLWD using the program	Tracking
		2) # of person-centered plans developed	Tracking
		3) # of care partners engaged with the program (there are different levels of engagement)	Tracking
		4) # and location of home and community visits	Tracking
		5) # and content of feedback and comments received from the client (PLWD and their care partners)	Tracking
		6) # and nature of connections or contacts with other COs	Tracking
		7) # of referrals to recreation-and-leisure-focused community organizations	Tracking
		8) # of facilitated referrals to other CO programs	Tracking
		9) # and nature of inappropriate referrals (those with high needs or in crisis that don't meet the program criteria)	Tracking
Intermediate Outcomes	Effectiveness	1) Has the program increased the quality of life of PLWD?	
		2) Has the program increased the quality of life of care partners of PLWD?	Interviews
		3) Has the program increased the feeling of social inclusion of PLWD?	Social Functioning-Dementia Survey
		4) Has the program increased the feeling of social inclusion of care partners of PLWD?	Interviews
		• 5) How much and in which areas are clients satisfied with the program?	Interviews
		6) Has the program increased the length of remaining at home and community for PLWD?	
		7) Has the program given care partners other options and support to avoid burnout or increase their ability to cope?	
		8) Has the program reduced the urgency for additional healthcare system support?	
		9) Are care partners more informed to easily navigate supports?	
Long - Term Outcome	Sustainability	Supply and demand	
		Waitlists	
		Community members making referrals	

Outcome Measures	Indicators	Data Collection Method	
	Number of referrals to SaskAbilities Dementia Friendly Life enrichment program made by clients and other institutions over the duration of the program	Tracking	
	Increase in the number of clients who fit the criteria requesting services from the program	Tracking	
	Number of positive responses from the private sector for funding to support program/volunteer program at SaskAbilities	Tracking	
	Increase the network of extended family and friends who volunteer in providing services to PLWD	Tracking	
	Number of partnerships created with the health authority and other possible funders	Tracking	
	Transferability	PLWDs have Person-Centered Plans [PCP] that list their preferred activities. The PCP is a tool that can help train new staff who are providing a respite to PLWD (i.e. home care is available in the area). This can include Day Wellness programs for PLWD	Tracking
		Several long-term care institutions (ex. Langenburg, Canora, and Yorkton) have requested recreation services that can be implemented within their facility. The preferred activities can be shared with staff and be implemented by the recreation worker at the facility	Tracking
		Volunteers or family members can complete community outings	
		A dementia video will be completed to identify the need for community-based programs for people living with dementia and their caregivers	Tracking
		Needs Assessment report identifying areas of support/needs for PLWD and their families	Tracking

Appendix B: SaskAbilities Dementia Friendly Life Enrichment Program Background and Interview Guide

Outcome Evaluation for the SaskAbilities Dementia Friendly Life Enrichment Program

The SaskAbilities Dementia Friendly Life Enrichment Program is supported by the Dementia Supports in Rural Saskatchewan (DSRS) initiative. The DSRS is a five-year (2019-2024) Collective Impact initiative undertaken by the Saskatchewan Population Health and Evaluation Research Unit (SPHERU), University of Regina, and funded in part by the Government of Canada's New Horizons for Seniors Program. The DSRS project seeks to improve public awareness of the stigma and social isolation experienced by People Living with Dementia (PLWD) and their care partners. Through the DSRS, SPHERU has supported eight collaborating organizations including the SaskAbilities Dementia Friendly Life Enrichment program that started in April 2021 and aims to enhance the quality of life of individuals living with dementia in Yorkton and surrounding rural communities.

The Saskatchewan Population Health and Evaluation Research Unit (SPHERU), at the University of Regina, is carrying out outcome evaluation to measure short-term, intermediate, and where applicable, long-term outcomes of the program. Interviews are part of the ongoing evaluation that aims to assess the outcomes of the project.

Participants would receive interview guides and consent forms prior to the interview. The consent form provides details on confidentiality and management of information generated from interviews.

Interview Guide

(The questions to be discussed during the interview are selected from the following list)

1. In what ways has the program increased the quality of life of PLWD?
2. How has the program increased the quality of life of the care partners?
3. In what ways has the program increased the feeling of social inclusion of PLWD?
4. To what extent has the program increased the feeling of social inclusion of care partners?
5. How much and in what areas are clients most satisfied with the program?
6. How has the program increased the length of time remaining at home and community for PLWD?
7. In what ways has the program given care partners other options and support to avoid burnout and increase their ability to cope?
8. To what extent has the program reduced the urgency for additional healthcare system support?
9. To what extent has the program helped care partners to be more informed to easily navigate supports? (mutually reinforcing)
10. How do extended family members and friends think of this program? How often do they volunteer to help PLWD and Care Partners at other times?
11. What would you (facilitators) do differently?
12. What is the value of having Caregivers choosing to participate in group activities after whose loved ones have passed?
13. What would be the strongest points to make a case for other stakeholders to support this program?