

YouQuest Young Onset Dementia

Final Report

Executive Summary

YouQuest Wellness Community for Young-Onset Dementia was a project implemented in order to support sustainability and growth following a successful pilot project (completed in 2018). Prior to the start of this project, YouQuest was offering full-day services to 10 people with young-onset dementia once per week. There was an extensive wait list and growing need for this unique adult day program. YouQuest is founded on the premise of providing an active, full-day service for younger people impacted by some form of dementia. YouQuest set out to meet the unique and individual needs of this age group with the intent to connect or re-connect them to the broader community providing dignity of care through individualized care, choice and independence.

The project goals, expected outcomes, activities and actual outcomes are listed in the table below:

Goals	Expected Outcomes	Activities	Outcomes
1. A safe, welcoming place for participants to have a good day	Expand services to support current, waitlisted, and new participants	Therapeutic recreation model to facilitate unique needs of each participant.	Successfully on-boarded all eligible/interested new participants. No waitlist remains.
2. Choices for an active, healthy quality of life.	Target = 36 Calgarians	Treat each individual with respect and dignity.	Target number of 36 people in the service has not yet been reached
3. A reliable support network for unpaid care partners and their families	Full-Day service increase to 3 days/week	Full-Service days with intentionally planned physical, spiritual, emotional and cognitive events	Effectively expanded to 2 full-day service days and maintained in varying formats despite restrictions and shutdowns.
4. Sustainability		Engage in community	Evaluations consistently point to the first three goals (column 1) as a YouQuest strength.
5. Scalability			Continued effort is required for achieving a sustainable future.

Key Takeaways: There were 4 key takeaways from the project (what we learned) which are expanded on further in the report:

1. In-Person Services – YouQuest’s service model is most effective offered in-person.
2. Resilience – Our team, families and participants are resilient.
3. Effective – The YouQuest service model works.
4. Growth – There is a strong desire to grow and share YouQuest with many more families.



Next Steps: There were 4 areas identified as next steps for YouQuest which are explained in detail later in the report:

1. Diversity, Equity and Inclusion
2. Increase Visibility
3. Sustainability
4. Transition Plan

Attachments: Along with the report that follows, please refer to the following separate documents:

1. Pilot Project Evaluation Report (completed prior to receipt of this grant, but is noted in the application and monthly reports)
2. Survey Results
 - a. Care Partner Survey Results (Spring and Fall 2021)
 - b. Participant Feedback Results (Fall 2021)
 - c. Volunteer Feedback Results (Fall 2021)
3. Photo presentation

Background

YouQuest Mission: “To promote health and well-being for people with young-onset dementia and their families by ensuring access to recreation therapy, counseling and peer support resources.”

YouQuest Goals:

1. A safe, welcoming place for participants to have a good day, providing choice for an active, healthy quality of life.
2. A reliable support network for unpaid care partners and families.
3. Increased public awareness of young-onset dementia, especially for employers, insurers and the health system.

YouQuest started in 2017 with what would be considered a “design phase” where it was confirmed that a full-day service model in a public recreation setting was needed for individuals with young-onset dementia.

In 2018 as an ‘implementation phase,’ YouQuest ran a pilot project with 10 participants that included an extensive evaluation process. The YouQuest design is a therapeutic recreation framework that addresses the five health domains (social, physical, cognitive, emotional and spiritual).

In 2019, following the pilot program, we determined the need to continue as an association and that is when AHS provided this grant which allowed for continued implementation of this brand-new service.

Project Goals:

1. A safe, welcoming place for participants to have a good day.
2. Choices for an active, healthy quality of life.
3. A reliable support network for unpaid care partners and their families.
4. Sustainability
5. Scalability

Project Outcomes:

1. Expand services to support current, waitlisted, and new participants.
2. Target = 36 Calgarians
3. Full-Day Services increased to 3 days per week

Expected Activities:

1. Therapeutic Recreation Model to facilitate unique needs of each participant.
2. Treat each individual with respect and dignity.
3. Full-Service Days with intentionally planned physical, spiritual, emotional and cognitive elements.
4. Engage in community

Highlights and Innovations

Like so many others, COVID wreaked havoc on our plans; however, YouQuest utilized the opportunity to get creative. Here is timeline breaking down highlights of the project:

- November 2019 – Project initiation with YouQuest operating 1 full-service day per week with 10 participants
- December 2019 – March 2020 – Secure rental space for increased service days, contractors provided contracts to support additional days (Recreation Therapist, Recreation Therapist Assistant, Volunteer Coordinator, Bookkeeper), Increased group size to 12.
- March 2020 – September 2020 – COVID lockdown, Board strategic sessions for continuity and re-entry plan; secure additional funding for IT migration for new database development including volunteer portal; ongoing communication with families; Completed Pilot Evaluation Report; Re-assess current participants (down to 8) plus assess 4 new ones; secure new venue for operations when in-person is allowed again;
- October 2020 – Re-Launch in-person services at new location. Increase to provide 2- service days by October 27. Increase participants to 16.
- December 2020 – COVID lockdown; Prepare for year-end giving drive; begin hiring for new Executive Director
- January 2021 – Board hires new Executive Director; Approval given to operate “Community Outreach Project” providing 2 hours of outdoor interaction and physical activities for participants and respite for care partners.
- July 2021 – Began “Modified Service Days” still meeting outdoors, but extending time in order to prepare for full-day service days (increase activity, re-establish routines); During this time, we saw 6 participants transition out due to progression of symptoms, but we welcomed 7 new participants leaving our wait-list at 0
- September 2021 – Re-establish contract with facility partner and begin full-service days offering two days per week with 16 participants and 4 in the intake process.

Innovations from this Project:

1. Community Outreach Project – YouQuest considered the best way to offer in-person services despite restrictions in place due to COVID. The Community Outreach Project allowed for participants to receive therapeutic recreation services, care partners to have a couple hours of respite, and provide for engagement with our invaluable engagement community.
2. Modified Service Days – Again, determining the best way to continue to offer services, yet strategically prepare for full-service days, these modified service days were all planned outdoors with the purpose of implementing routines while maintaining connection to the broader community. Increased respite for care partners was appreciated.

Stakeholder Engagement

This was a unique project in that the design, implementation and evaluation phase occurred during the pilot project during which stakeholder engagement was critical to forming the continued full-service day model. Through this project to expand and create sustainability for YouQuest, stakeholder engagement was ongoing.

People Living With Dementia: Our Recreation Therapists and Volunteers remained closely in touch with our participants even through the lock-down periods. This interaction provided opportunity to discover their needs and

concerns and develop programming to suit their individual needs. For example, during the Community Outreach Project, we discovered that some participants' physical ability declined significantly during the lengthy lockdown. We established 1-1 support at their home and outside of their homes to work to re-establish physical agility to allow continued participation with YouQuest when full-service days resume. Recreation Therapists and Volunteers are constantly listening and asking participants questions to make improvements and to meet their individual needs.

Care Partners: Again, we remained in touch with Care Partners to ensure they were faring well during lockdowns. The Community Outreach Project concept was implemented with feedback from care partners. Then, we completed a survey in the spring of 2021 to assess the effectiveness of this project.

Recreation Therapists and other YouQuest contractors met regularly throughout this project timeframe to discuss best practices, modifications required, and new ideas to put in place to best support people living with young-onset dementia.

Board of Directors: Regular updates at board meetings and a couple of strategic planning sessions ensured that the board vision and oversight of the organization was implemented.

Volunteers: Two volunteer training sessions were implemented during this project and a series of training modules specific to YouQuest was developed. Volunteers were a part of planning and implementing the Community Outreach Project, planning a family social in the summer, and with being able to provide their feedback through a formal survey.

Project Performance/Evaluation

Performance Related to Activities

1. Volunteer training modules were developed specific to YouQuest and young-onset dementia.
2. A new database to track participants, care partners, donors, and volunteer hours was implemented. This is to assist with future reporting and sustainable activities.
3. Our model for therapeutic recreation services was able to be scaled down during the lock-down, but the results and improvements noted in participants based on feedback from care partners pointed to improved quality of life during an extremely difficult period. It is good to know that we are able to scale down or scale up our services and achieve our goals.

Performance Related to Outcomes

Project Goals:

1. A safe, welcoming place for participants to have a good day – Evaluations of the YouQuest Services point to this goal as a strength of the program.
2. Choices for an active, healthy quality of life - Evaluations of the YouQuest Services point to this goal as a strength of the program
3. A reliable support network for unpaid care partners and their families. - Care Partners feedback accents success in this area.
4. Sustainability – The circumstances causing closures during this project impacted our ability to feel like we could achieve sustainability and continued effort is required.
5. Scalability – Successful growth points to a scalable model but has not been implemented due to restrictions

Project Outcomes:

1. Expand services to support current, waitlisted, and new participants. – Successfully on-boarded all eligible and interested new participants. No waitlist remains.
2. Target = 36 Calgarians – Due to transitions and the restrictions, our target number has not yet been reached.
3. Full-Day Services increased to 3 days per week – Effectively expanded to 2 full-day service days despite the restrictions.

Lessons Learned and Areas for Improvement

Though this project, we learned that the YouQuest service model is most effective when offered in person. Our focus is to provide respite and to reduce isolation for our families. In addition, the goal is to connect participants with the broader community around them. Despite restrictions that would limit in-person services, we discovered that it does not have to stop the YouQuest service model.

Through COVID and all the changes faced during this last year, we learned that our team, families and participants are resilient and open and excited to try anything that will benefit the participants. This allows us the freedom and flexibility to continue to be creative and implement services in different ways that will benefit our participants and care partners.

We also discovered that the YouQuest model works. Feedback has shown that the YouQuest model increases community and social engagement for our participants and care partners; there has been improved quality of life; that this is an innovative person-centered care program

Finally, we learned that there is a strong desire to see YouQuest continue to succeed and to offer services to more families in Calgary and beyond.

Success Stories

Our greatest success stories come from our people who are a part of the YouQuest service days. Here are some direct quotes from three of our main stakeholder groups that point to success over the past two years. All have asked to remain anonymous.

Participant 1: “The interaction with other people is great and it is a good time to be able to work on my brain.”

Participant 2: “I didn’t talk as much before but meeting new people, trying new things have motivated me to talk more.”

Participant 3: “It is a safe space to talk about things – people understand.”

Care Partner 1: “This is a time where I can work on my own mental health and not worry about my husband for a few hours as I know he’s in very good hands having a great day.”

Care Partner 2: “There is no one judging him, and everyone is so kind. It gives him a sense of independence which is so important when other things seem to be slipping away from him and me.”

Care Partner 3: “YouQuest has brought our brother back to life. At home he is more active, helps with home chores and activities. His sense of humour is back and he is showing interest in life. He is engaging in meaningful conversations.”

Volunteer 1: “I appreciate the ability to interact with participants ensuring their days are fulfilled.”

Volunteer 2: “My awareness of the issues that care partners and participants face has increased.”

Volunteer 3: “I love the exploratory nature of YouQuest. It feels like real time research into enabling a higher quality of life for participants.”

Sustainability

Our plan for sustainability and continuation of services includes the following:

1. Diversity, Equity, and Inclusion – Are there ways that YouQuest can better support BIPOC communities? What will this look like, how can we do this? Will it be accepted by other communities? How will this fit within our plan for sustained growth? For this, YouQuest has applied for funding to do an environmental scan to see if there are areas within Calgary to target and begin to work toward developing partnerships.
2. Increase Visibility – To grow, YouQuest needs to increase visibility and make sure we are well known in all quadrants of Calgary. This will be done by hiring a Marketing & Communications coordinator to help us focus our efforts in this area.
3. Transition Plan – We have learned that there is a need for a transition plan for our participants. When participants can no longer tolerate a full-service day, and they are not entering some long-term care setting, is there a way we can provide additional support? Can we offer a half-day that looks like the full-service day model by following guiding principles of dignity of choice, connecting to community and providing respite for loved ones?
4. Sustainability – Can we consider our business model and discover ways to become more self-sustaining without fully relying on grants and donations for operations?