

# Process Evaluation of a Dementia-Friendly Communities Workshop

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**Abstract**

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**Background:** One of the goals in the *Washington State Plan to Address Alzheimer’s Disease and Other Dementias* is “to infuse age-friendly and dementia-friendly concepts into local communities.” To build dementia-friendly communities (DFCs), the University of Washington Memory and Brain Wellness Center (MBWC) works with its partners to develop events, programs, and resources that ensure that individuals living with memory loss remain active members of the community and have opportunities to stay active, be connected, and give back. One such MBWC program is “Our Time Has Come” (OTHC). Originally offered as a program in the general community, OTHC was administered for the first time in a senior living facility in the spring of 2017. **Purpose:** The purposes of this process evaluation were: (1) to evaluate

OTHC's primary objective (i.e. to provide an accessible, meaningful, and successful opportunity for people living with memory loss to design and complete a DFCs project); (2) to understand the program experience of OTHC participants, OTHC staff, and staff members of the hosting senior living community; and (3) to examine OTHC's underlying mechanism, including immediate outcome (i.e. perceived accessibility), mediators (i.e. perceived impact on the community, sense of success), and intermediate outcomes (i.e. sense of purpose, self-esteem, general and community services self-efficacy, sense of connection to the community).

**Methods:** This process evaluation adopted a descriptive cross-sectional design using qualitative methods, including a focus group and semi-structured individual interviews. Purposive sampling was used to ensure that participants of this process evaluation consisted of OTHC participants, OTHC staff, and senior living staff. Thematic analysis was used to analyze focus group and interview transcripts. **Results:** One focus group and 12 individual interviews were conducted with 7 OTHC participants, 2 OTHC staff, and 3 senior living staff. OTHC participants completed their DFCs project within the 8-week program duration. Thematic analysis revealed four main themes relevant to interviewees' overall experience or overall impression of OTHC: (1) *a positive experience overall*, (2) *from initial confusion to "I'm glad I did it!"*, (3) *a cohesive group made up of the right mixture of people*, and (4) *successful participant recruitment and retention*. OTHC achieved its primary objective, immediate outcome, and mediators, and partially achieved its intermediate program outcomes. **Conclusion:** OTHC can be successfully implemented in a senior living community setting. OTHC completers, OTHC staff, and senior living staff all had a positive overall experience of the program. Program participants' individual differences (e.g. personal calling, success appraisal, ceiling effect, etc.) may affect the program's

intermediate outcomes. The MBWC should ensure that participants understand the program purpose at the time of enrollment.

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## Chapter 1. INTRODUCTION

Dementia is a major neurocognitive disorder, characterized by impairments in both cognitive function and performance of daily activities (American Psychiatric Association, 2013). Common forms of dementia include Alzheimer's dementia, vascular dementia, dementia with Lewy bodies, and mixed dementia (Alzheimer's Association, 2017). Even though dementia is not part of normal aging, advanced age is the greatest risk factor for dementia. With an aging population worldwide, the number of individuals influenced by dementia is expected to grow exponentially. In the United States, estimates suggest that 4.5 million Americans had Alzheimer's dementia in 2010 and this number will nearly triple and reach 13.8 million by 2050 (Herbert, Weuve, Scherr, & Evans, 2013). In Washington State, 92,451 Washington residents age 65 years and older had Alzheimer's dementia in 2010 and this number is expected to exceed 230,000 by 2040 (Washington State Department of Social and Health Services, 2014).

As the number of individuals with dementia increases, so does the demand for programs and services that provide early assessment, diagnosis, education, and support for these individuals and their families. The University of Washington Memory and Brain Wellness Center (MBWC) provides diagnosis, treatment, education, and support to approximately 1,500 individuals age 40 and older living in the Puget Sound Region and beyond who may be experiencing changes in memory and thinking abilities caused by a degenerative brain disease (Chapman, 2016). To achieve its mission to promote the wellbeing of persons living with memory loss and their families, the MBWC adopts three broad strategies: (1) providing exceptional care, (2) advancing scientific understanding through research, and (3) building dementia-friendly communities (DFCs).

## 1.1 DEMENTIA-FRIENDLY COMMUNITIES (DFCs)

DFCs refer to communities in which people with memory loss belong and live well (Becker, 2016). The most common definition of *community* in terms of DFCs is a geographical location, such as a specific village, town, city, region, or country (Alzheimer's Disease International, 2016a). The aim of DFCs is to give people with dementia a purpose in life (Alzheimer's Disease International, 2016b). The vision of DFCs is:

“to transform the whole community including its people, environment and services so that we will be able to meet the goals and aspirations of people with dementia to take part in a range of opportunities such as ongoing participation in working, volunteering, hobbies and leisure activities and meaningful social interaction.” (Alzheimer's Disease International, 2016b, p. 2)

The inception of the global DFCs movement can be traced back to the Japanese Government's nationwide campaign, 10-Year Plan to Understand Dementia and Build Community Networks, launched in 2004 (Alzheimer's Disease International, 2016b). In 2012, the World Health Organization (WHO) and Alzheimer's Disease International (ADI) released a joint report, *Dementia: A Public Health Priority*, to raise awareness of dementia, to articulate a public health approach, and to advocate for action at international and national levels. In the joint report, DFCs was referred to as a promising approach to normalize dementia, or the acceptance of dementia as a disability and the inclusion of people with dementia in society as much as possible. Since currently there is no cure for dementia, to support a better life for people living with dementia and their families, over 30 countries around the world are building DFCs (ADI, 2016b).

In the United States (U.S.), to prepare the nation for the impacts of dementia, President Obama signed into law the National Alzheimer's Project Act in 2011, followed by the release of the *National Plan to Address Alzheimer's Disease* in 2012 (U.S. Department of Health and

Human Services, 2012). The term of DFCs was first introduced to the U.S. national Alzheimer plan in its 2015 update (U.S. Department of Health and Human Services, 2015). Currently, The Administration for Community Living, through its Alzheimer’s Disease Initiative-Specialized Supportive Services and Alzheimer’s Disease Supportive Services Program cooperative agreements, allocates available federal funding to support state and local projects, that include DFCs components (U.S. Department of Health and Human Services, 2016).

In Washington State, the State released its Alzheimer State plan, *Washington State Plan to Address Alzheimer’s Disease and Other Dementias*, in January 2016 (Washington State Department of Social and Health Services, n.d.). The *Washington State Plan* identifies goals, strategies and recommendations as a blueprint for action. One of the goals in the *Washington State Plan* is to “prepare communities for significant growth in the dementia population” (Washington State Plan to Address Alzheimer’s Disease and Other Dementias, 2016, p. 3). One of the strategies to achieve this goal is “to infuse age-friendly and dementia-friendly concepts into local communities” (p. 3).

The MBWC’s organizational strategy of building DFCs aligns with Washington State’s strategy to infuse age-friendly and dementia-friendly concept into local communities. To build DFCs, the MBWC works with its partners to develop events, programs, and resources that ensure that individuals living with memory loss remain active members of the community and have opportunities to stay active, be connected, and give back (MBWC, 2016). One such MBWC program is “Our Time Has Come” (OTHC).

## 1.2 OUR TIME HAS COME: A DEMENTIA-FRIENDLY COMMUNITIES WORKSHOP

OTHC is an 8-week DFCs workshop where people with early stage memory loss come together to learn what other local DFCs movements have accomplished, consider their own

strengths and interests, and carry out a group action project of their choice to make their community more dementia-friendly. Each weekly workshop lasts for approximately 2 hours. The target group size is 8 to 12 participants plus one to two group facilitators and at least one volunteer.

### 1.2.1 *Brief History of OTHC*

OTHC was developed in house in the MBWC by its Program Manager of Community Education and Impact, Marigrace Becker, MSW. Ms. Becker created the program based on an effective group facilitating process that she discovered and piloted with “The Gathering Place”, a weekly program of stimulating activities and discussions for people with early stage memory loss at the Greenwood Senior Center, in 2013. The name of the program, OTHC or Our Time Has Come, comes from a song written by members of The Gathering Place with song writer Linda Waterfall (access <https://www.youtube.com/watch?v=loms4xjIRMU> to listen to the song). The unique group facilitating process developed by Ms. Becker incorporates action learning principles (i.e. plan-act-observe/reflect), adult learning principles (e.g. self-directed, goal-oriented, etc.), and dementia-friendly principles (e.g. Keep the participants with memory loss front and center, incorporate loose structure that provides a step-by-step process that moves toward success for individuals and the group, etc.), tackling various learning domains (i.e. cognitive, affective, behavioral), and supporting various learning styles (e.g. visual, auditory, etc.).

Funded through the program manager salary, philanthropic donations, and in-kind support of community partners, OTHC was offered for the first time in the summer of 2016, at no charge to participants with memory loss and their care partners. A total of 13 people (8 participants and 5 care partners) enrolled in the program, among whom 8 (5 participants and 3 care partners) completed the program. The first OTHC group decided to host an intergenerational

event to raise dementia awareness and build connections with kids at a local day camp. The 2<sup>nd</sup> cycle of OTHC was offered in the spring of 2017, with some adjustments in the program format: First, participants of the Summer 2016 session could bring their care partners if desired, whereas the Spring 2017 session was offered exclusively to people experiencing memory loss. Second, the Summer 2016 session was open to all Seattle residents with memory loss (held in an apartment building of the Seattle Housing Authority that allowed public access), whereas the Spring 2017 session was held in a senior living community and was offered exclusively to residents of the hosting senior living community. As part of the OTHC pilot work, the MBWC made these program format adjustments to explore (1) which model (e.g. with vs. without care partners) may allow for greater inclusion and engagement of participants with memory loss, and (2) the feasibility of implementing OTHC in different settings (e.g. publicly accessible space vs. senior living community).

### 1.2.2 *OTHC Program Objectives and Anticipated Outcomes*

The primary objective of OTHC is to provide an accessible, meaningful, and successful opportunity for people living with memory loss to design and complete a DFCs project. “Accessible” means that the program is designed in a way that everyone feels included, everyone feels welcome, and everyone can contribute. “Meaningful” refers to having a serious, important, or useful quality or purpose. “Successful” means that participants feel satisfied about the level of support and resources provided by the program, feel satisfied about what they have accomplished throughout the program, and feel they have met their action project goals.

The ultimate objective of OTHC is to counter internalized oppression among persons experiencing memory loss. “Internalized oppression” refers to an unconscious, involuntary response to oppression in which members of the marginalized group believe the negative

stereotypes and expectations of their group based on messages that they have received from the oppressor (David, 2013). In the context of OTHC, internalized oppression refers to people with memory loss believing the myths or misinformation (e.g. people with memory loss are not valuable, have nothing to offer, or do not matter; people with memory loss lack power, authority, or ability; people with memory loss do not belong; etc.) that the society communicates to them about people with memory loss.

The anticipated OTHC program outcomes are listed below:

1. Participants will perceive the program as accessible to them.
2. Participants will have an increased sense of purpose.
3. Participants will believe that they have an impact on their community (geographical community).
4. Participants will have increased self-esteem.
5. Participants will have increased self-efficacy over their abilities to make a difference in their life and in their community (geographical community).
6. Participants will have an increased sense of connection to their community (memory loss community and the geographical community).

“Sense of purpose” refers to the degree to which a person derives meaning in life. “Self-esteem” refers to a person’s self-evaluation of his or her own worth and attitudes towards self. “Self-efficacy” refers to a person’s belief in his or her own ability to make a difference in life while “community services self-efficacy” refers to a person’s belief in his or her own ability to make a difference in the community (geographical). “Sense of connection to the community” refers to a person’s feeling of belonging within the community (i.e. memory loss community and the geographical community).

### 1.3 PROCESS EVALUATION AIMS

Ms. Becker, the creator of OTHC, envisions disseminating the program to the rest of Washington State. However, it would be risky to attempt a state-wide dissemination before extensive formal evaluation of the program. As part of the evaluation efforts of OTHC, this process evaluation was conducted with the Spring 2017 OTHC session. The aims of this process evaluation were:

1. To evaluate the achievement of OTHC's primary objective (i.e. to provide an accessible, meaningful, and successful opportunity for people living with memory loss to design and complete a DFCs project);
2. To understand the program experience of OTHC participants, the OTHC staff (facilitator and volunteer), and staff members of the hosting senior living community.
3. To examine OTHC's underlying mechanism by assessing the program's immediate outcome (i.e. perceived accessibility), mediators (i.e. perceived impact on the community, sense of success), and intermediate outcomes (i.e. sense of purpose, self-esteem, general and community services self-efficacy, sense of connection to the community).

As illustrated in Figure 1.1, it was hypothesized that:

- **Pathway A:** a) *dementia-friendly facilitation elements* (e.g. multiple senses, emotional memory, procedural/habit memory, simple 1-phrase instructions, visual aids that show the instructions and overall agenda, support as needed from volunteer or care partner, etc.) and b) *setting group expectations* (creating group agreements with participants and checking in at the end of each workshop) would lead to *perceived accessibility* (immediate outcome) of the program among OTHC participants.

- **Pathway B:** c) *verbal reinforcement* of the ‘needs’ in the community (i.e. stigma and lack of dementia-friendliness) and of participants’ invaluable role as experts in addressing the community needs would increase participants’ *sense of purpose* (intermediate outcome).
- **Pathway C:** d) *goal setting* (having participants select a community-based group action project and develop project objectives), e) *fast program results* (group project being completed in 8 weeks), and f) *evaluation of goal attainment* (Did we meet our project objectives?) would provide a quick sense of completion/accomplishment, which would in turn increase participants’ *perceived impact* on their geographical community of choice (mediator) and their *sense of success* (mediator).
- An increase in *perceived impact* and *sense of success* would then increase participants’ *sense of purpose* (intermediate outcome, **Pathway D**), *self-esteem* (intermediate outcome, **Pathway E**), and *self-efficacy* (intermediate outcome, **Pathway E**).
- **Pathway F:** g) *high expectations* for each participant (i.e. you are the expert on your own experience, you have gifts to contribute, you can make a difference) to combat the myth that people with memory loss are not capable, h) *strength identification and application* (identification of personal strengths and then sharing those with the entire group), i) *opportunities to help* (chances for group members to help each other), j) *opportunities for personal choice, autonomy, and impact* on the whole process (e.g. deciding the project focus area, setting daily goals that contribute to the final project objectives, designing/implementing the project, brainstorming, decision-making, etc.), k) *opportunity for leadership* (taking the lead/facilitating parts of the project, responsibility through homework assignments based on participants’ abilities/interests, allowing for risk-taking, etc.), l) *validation of participants’ personal experiences and input* through incorporating

these into the project plan, and m) *examples of contributions made by others with memory loss to the community* (i.e. memory loss community and geographical community) would increase participants' *self-esteem* and *self-efficacy* (intermediate outcomes).

- **Pathway G:** n) *community assessment* (geographical community) from the view of people with memory loss, o) *consistent attention to the wider community* (geographical community) as the action project audience, and (p) *opportunities to interact with other participants with memory loss* would increase participants *sense of connection* to others with memory loss and their community of choice (intermediate outcome).
- Increased *sense of purpose* (**Pathways H**), increased *self-esteem* and *self-efficacy* (**Pathway I**), and increased *sense of connection* (**Pathway J**) would counter/decrease *internalized oppression* (ultimate outcome)

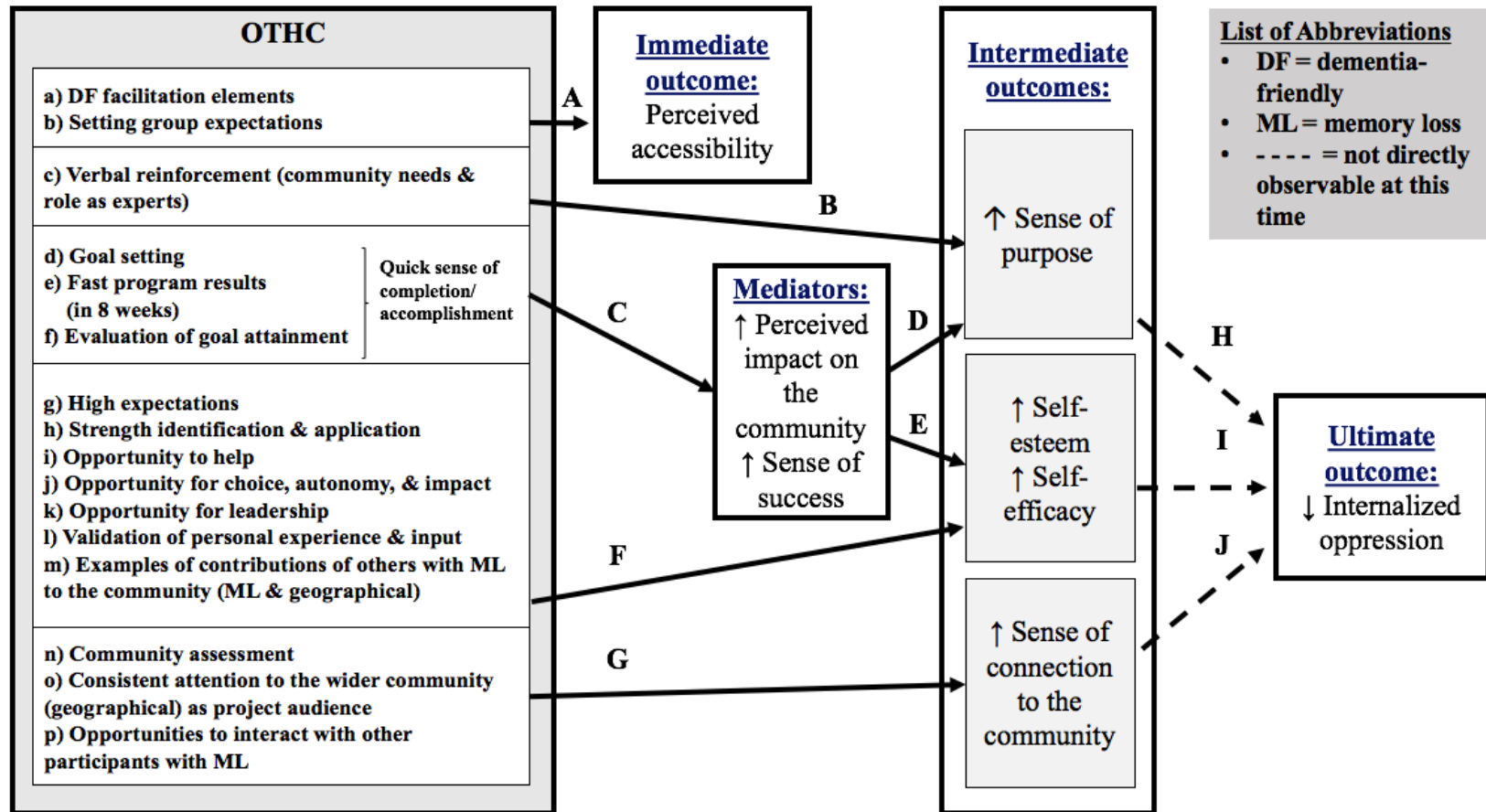


Figure 1.1. OTHC Conceptual Framework.

The specific evaluation questions are as follows:

1. Did OTHC achieve its primary program objective (i.e. to provide an accessible, meaningful, and successful opportunity for people living with memory loss to design and complete a DFCs project)?
2. How did OTHC participants perceive their group DFCs project (mediators)?
3. What was the overall impression or overall experience of OTHC from the perspectives of OTHC participants, senior living staff, and OTHC staff?
4. How accessible was OTHC (immediate outcome)?
5. How did OTHC influence participants' sense of purpose, self-esteem, general self-efficacy, community services self-efficacy, sense of connection to other OTHC participants, and sense of connection to the geographical community of choice (intermediate outcomes)?
6. What are barriers and facilitators of implementing this type of program in a senior living community setting?

The ultimate outcome of OTHC, to counter internalized oppression among persons experiencing memory loss, and the hypothetical Pathways H, I, and J, were not evaluated in this process evaluation because they were beyond the scope of a typical process evaluation and should be addressed by a future impact evaluation.

## Chapter 2. METHODS

### 2.1 DESIGN AND SAMPLING

This process evaluation incorporated a descriptive cross-sectional design (Grembowski, 2016) using qualitative methods, including a focus group and semi-structured individual interviews. Purposive sampling was used to ensure that participants of this process evaluation consisted of three types of people: 1) OTHC participants, 2) OTHC staff (group facilitator and volunteer), and 3) senior living staff members who were involved with OTHC implementation (referred to as “senior living staff” from this point on). See Table 2.1 for eligibility criteria of this process evaluation by participant group.

Table 2.1. Eligibility Criteria by Participant Group

Process evaluation participant group	Eligibility Criteria
OTHC participants	All participants of the 2017 Spring OTHC session were eligible to participate in this process evaluation. To be eligible for OTHC, an individual had to (1) be a resident at the senior living facility hosting the 2017 spring OTHC session, (2) have self-reported memory loss or cognitive impairment, (3) be willing to talk about their memory loss or cognitive impairment, and (4) want to make a difference in the community.
OTHC group facilitator and volunteer	The OTHC program facilitator or volunteer who was at least 18 years old was eligible for this process evaluation.
Senior living staff members	Staff members of the hosting senior living community who were at least 18 years old and who were involved with OTHC implementation were eligible to participate in this process evaluation.

The rationale of using a descriptive design was to create a profile of what went on in the program (Grembowski, 2016). The rationale of the cross-sectional design was to capture participants’ experience of the program at one point in time (within 2 weeks of program completion) to reduce recall bias. Qualitative methods were chosen to understand the processes

that led to observed outcomes of the program and potentially generate new causal explanations of why the program did or did not work (Grembowski, 2016, p. 159). The rationale of a focus group was to give OTHC participants an opportunity to reflect on their action project as a group, considering that group interaction and discourse might produce new insights that would not otherwise be produced in individual interviews. The rationale of semi-structured individual interviews was to provide OTHC participants an opportunity to share more intimate information, such as how the program had affected them on a personal level (e.g. self-esteem, sense of purpose, etc.), in a more private setting, as well as to allow OTHC staff and senior living staff an opportunity to share their observations and feedback on the program.

## 2.2 PROGRAM

The Spring 2017 OTHC session was facilitated by 1 group facilitator and 1 volunteer. Ms. Becker, the creator of OTHC, served as the group facilitator for this cycle of OTHC and trained the volunteer herself. The volunteer was an undergraduate psychology student. Before the program began, Ms. Becker gave the volunteer two 2-hour, in-person training sessions on OTHC (4 hours total). The duration of the OTHC workshop series was 8 weeks. The duration of each weekly workshop was 2 hours. Each workshop purposefully incorporates a similar structure to include: welcome, review group agreements, review of overall agenda, review of session goals(s), individual, paired and group “thinking” (Weeks 1-3), individual, paired, and group “doing” (Weeks 4-7), planning next steps, assigning homework as needed, a brief review/reflection, and a closing song (singing the song *Our Time Has Come*). See Table 2.2 for the weekly workshop outline.

Table 2.2. Spring 2017 OTHC Weekly Workshop Outline

Workshop	Summary of activities	Program theory elements addressed (The alphabet listed before each program element below is the same as the alphabet assigned to represent each program element in Figure 1.1. OTHC Conceptual Framework)
<b>Workshop 1</b> Our Stories, Our Strengths: Introduction to DFCs	<ul style="list-style-type: none"> <li>• Establish group agreements</li> <li>• Introduce DFCs</li> <li>• Guest speaker or video about DFCs</li> <li>• Inventory personal/group strengths</li> <li>• Establish team name</li> <li>• Create team flag/banner</li> </ul>	a) Dementia-friendly facilitation elements b) Setting group expectations c) Verbal reinforcement d) Goal setting f) Evaluation of goal attainment g) High expectations h) Strength identification and application j) Opportunity for choice, autonomy, and impact l) Validation of personal experience and input m) Examples of contributions of others with memory loss to the community
<b>Workshop 2</b> Our Community: What's working, what's not? Identifying our purpose	<ul style="list-style-type: none"> <li>• Small group discussion: barriers and bridges to community</li> <li>• Large group reflection on themes</li> <li>• Voting on project focus</li> </ul>	a) Dementia-friendly facilitation elements b) Setting group expectations c) Verbal reinforcement d) Goal setting f) Evaluation of goal attainment j) Opportunity for choice, autonomy, and impact l) Validation of personal experience and input n) Community assessment o) Consistent attention to the wider community p) Opportunities to interact with other participants with memory loss
<b>Workshop 3</b> Choosing our project. Creating an action plan.	<ul style="list-style-type: none"> <li>• Choose project to accomplish the group objective</li> <li>• Create list of action steps</li> <li>• Assign homework</li> </ul>	a) Dementia-friendly facilitation elements b) Setting group expectations d) Goal setting f) Evaluation of goal attainment g) High expectations j) Opportunity for choice, autonomy, and impact k) Opportunity for leadership l) Validation of personal experience and input n) Community assessment o) Consistent attention to the wider community p) Opportunities to interact with other participants with memory loss
<b>Workshop 4</b> Working Together	(Tailored to fit the DFCs project chosen by the Spring 2017 OTHC participants) <ul style="list-style-type: none"> <li>• Review homework</li> <li>• Decide basic event info for discussion group</li> <li>• Individual, paired and large group discussion – tips for maintaining relationships with people with memory loss</li> <li>• Develop plan for how to get additional tips</li> </ul>	a) Dementia-friendly facilitation elements b) Setting group expectations d) Goal setting f) Evaluation of goal attainment g) High expectations j) Opportunity for choice, autonomy, and impact k) Opportunity for leadership

	<ul style="list-style-type: none"> <li>Assign homework</li> </ul>	<ul style="list-style-type: none"> <li>l) Validation of personal experience and input</li> <li>n) Community assessment</li> <li>o) Consistent attention to the wider community</li> <li>p) Opportunities to interact with other participants with memory loss</li> </ul>
<b>Workshop 5</b> Working Together	<p>(Tailored to fit the DFCs project chosen by the Spring 2017 OTHC participants)</p> <ul style="list-style-type: none"> <li>Add to list of tips, by reviewing homework</li> <li>Choose top tips to use in guide</li> <li>Discuss graphic design for guide</li> <li>Discuss and decide ways to present the information</li> <li>Assign homework</li> </ul>	<ul style="list-style-type: none"> <li>a) Dementia-friendly facilitation elements</li> <li>b) Setting group expectations</li> <li>d) Goal setting</li> <li>f) Evaluation of goal attainment</li> <li>g) High expectations</li> <li>j) Opportunity for choice, autonomy, and impact</li> <li>k) Opportunity for leadership</li> <li>l) Validation of personal experience and input</li> <li>o) Consistent attention to the wider community</li> <li>p) Opportunities to interact with other participants with memory loss</li> </ul>
<b>Workshop 6</b> Working Together	<p>(Tailored to fit the DFCs project chosen by the Spring 2017 OTHC participants)</p> <ul style="list-style-type: none"> <li>Review homework including the draft guide</li> <li>Make any necessary revisions</li> <li>Review design for guide</li> <li>Make any necessary revisions</li> <li>Review ways to present information; Assign parts to people</li> <li>Practice presentation</li> <li>Assign homework</li> </ul>	<ul style="list-style-type: none"> <li>a) Dementia-friendly facilitation elements</li> <li>b) Setting group expectations</li> <li>d) Goal setting</li> <li>f) Evaluation of goal attainment</li> <li>g) High expectations</li> <li>j) Opportunity for choice, autonomy, and impact</li> <li>k) Opportunity for leadership</li> <li>l) Validation of personal experience and input</li> <li>o) Consistent attention to the wider community</li> <li>p) Opportunities to interact with other participants with memory loss</li> </ul>
<b>Workshop 7</b> Working Together	<p>(Tailored to fit the DFCs project chosen by the Spring 2017 OTHC participants)</p> <ul style="list-style-type: none"> <li>Reflect on presentation</li> <li>Review homework</li> <li>Make any potential revisions to guide based on presentation feedback</li> <li>Reflect on design for guide and make a decision</li> <li>Brainstorm and decide where to publish/post guide at the senior living community</li> <li>Assign homework</li> </ul>	<ul style="list-style-type: none"> <li>a) Dementia-friendly facilitation elements</li> <li>b) Setting group expectations</li> <li>d) Goal setting</li> <li>f) Evaluation of goal attainment</li> <li>g) High expectations</li> <li>j) Opportunity for choice, autonomy, and impact</li> <li>k) Opportunity for leadership</li> <li>l) Validation of personal experience and input</li> <li>o) Consistent attention to the wider community</li> <li>p) Opportunities to interact with other participants with memory loss</li> </ul>
<b>Workshop 8</b> Celebrating our success. Reflecting on our process.	<p>(Tailored to fit the DFCs project chosen by the Spring 2017 OTHC participants)</p> <ul style="list-style-type: none"> <li>Report on proposal for guide distribution</li> <li>Reflect on presentation and program experience (program evaluation activity)</li> <li>Celebration</li> <li>Discuss next steps with the senior living community social worker</li> </ul>	<ul style="list-style-type: none"> <li>a) Dementia-friendly facilitation elements</li> <li>b) Setting group expectations</li> <li>d) Goal setting</li> <li>f) Evaluation of goal attainment</li> <li>j) Opportunity for choice, autonomy, an impact</li> <li>k) Opportunity for leadership</li> <li>l) Validation of personal experience and input</li> <li>o) Consistent attention to the wider community</li> <li>p) Opportunities to interact with other participants with memory loss</li> </ul>

### 2.3 OTHC PARTICIPANTS

The target group size of the Spring 2017 OTHC session was 10 participants. The Memory Fitness Lead at the senior living facility where the Spring 2017 OTHC session occurred served as the senior living community champion of OTHC. The community champion recruited participants using a flyer supplied by the MBWC (See Appendix A) and screened potential participants for their OTHC eligibility. To be eligible for this cycle of OTHC, an individual had to (1) be a resident at the hosting senior living community, (2) have self-reported memory loss or cognitive impairment, (3) be willing to talk about their memory loss or cognitive impairment, and (4) want to make a difference in the community.

### 2.4 THE EVALUATOR

The evaluator was a Master of Public Health student who had 5 years of experience working with older people with dementia as a music therapist. The evaluator spoke English and Mandarin (native language). The evaluator had interviewed older adults with and without cognitive impairment in English for two research studies prior to this process evaluation.

### 2.5 DATA COLLECTION

The evaluator observed each weekly OTHC workshop and reviewed relevant program documents to familiarize herself with the program. During each weekly observation, the evaluator checked program fidelity using a weekly checklist developed by the evaluator (See Appendix B) and the weekly session plans provided by the OTHC facilitator (See Appendix C). During Week 8's OTHC workshop (the last workshop), the evaluator verbally invited OTHC participants to take part in this process evaluation by (1) attending an end-of-the program focus

group (occurred during Week 8's workshop) and (2) completing a follow-up individual interview within 2 weeks of OTHC completion. The evaluator also invited the OTHC facilitator, the OTHC volunteer, and senior living staff to participate in this process evaluation by completing an individual interview within 2 weeks of OTHC completion. All individual interviews were semi-structured, in-person, and conducted at a place convenient to the interviewee (e.g. the senior living community, a coffee shop suggested by the interviewee, etc.). The evaluator led the focus group and conducted all individual interviews. The focus group and all individual interviews were audio-recorded using a digital recorder. At the beginning of the focus group and each individual interview, the evaluator (1) obtained oral informed consent from the process evaluation participants (i.e. OTHC participants, OTHC staff, senior living staff) and (2) asked the participants to fill out an anonymous demographic form (See Appendix D). Some of the interview questions were modified from the interview questions used in Olsen et al.'s (2015) qualitative study on the experience of an exercise program of people with dementia. Additionally, a PowerPoint consisting of photos from each week's workshop was used to accompany interview questions about program activities, since it is recommended to use cues and prompts to maximize responses when interviewing people with cognitive impairment (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Considering that OTHC participants had self-reported memory loss or cognitive impairment, the evaluator decided to conduct member checking at the time of data collection, asking clarifying questions and summarizing main points brought up by the interviewees throughout the focus group and individual interviews to ensure that she understood the interviewees correctly. For focus group questions and individual interview questions see Appendix E and Appendix F.

## 2.6 ETHICS

The University of Washington Institutional Review Board reviewed this process evaluation in February 2017, and determined that the proposed evaluation activity was not research, as defined by federal and state regulations. See Appendix G.

## 2.7 DATA ANALYSIS

Audio recordings of the focus group and all individual interviews were transcribed verbatim by professional transcription services. The evaluator checked all transcripts against the original audio recordings for accuracy. Transcripts were analyzed using thematic analysis, following the 6-phase guide proposed by Braun and Clarke (2006): (1) familiarizing yourself with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report. Since thematic analysis is not wedded to any pre-existing theoretical framework, it can be used as an essentialist or realist method, a constructionist method, or a contextualist method (Braun & Clarke, 2006). In this process evaluation, the evaluator used thematic analysis as a realist method, which “reports experiences, meanings and the reality of participants” (Braun & Clarke, 2006, p. 81). After the evaluator completed the first five phases and generated a codebook (codes were generated inductively, grouped into themes, and then reorganized by evaluation questions), the evaluator and a second reviewer independently coded all transcripts using the codebook. The initial inter-reviewer agreement was 72%. The two reviewers met in person to discuss discrepancies in coding results. After revising and combining several codes that overlapped, the two reviewers reached consensus on all codes. The evaluator then proceeded to the 6<sup>th</sup> phase, “producing the report”.

## Chapter 3. RESULTS

### 3.1 DEMOGRAPHICS

A total of 1 focus group and 12 individual interviews were completed for this process evaluation. Seven out of the 10 OTHC participants completed the program (“OTHC completers). Among the three who did not complete the program, two dropped out because of physical health issues (back pain and knee pain), while one did not provide a specific reason. All 7 OTHC completers participated in the end-of-the program focus group; each of them also completed a follow-up individual interview. The focus group lasted for approximately 35 minutes. Individual interviews with OTHC participants lasted between 20 to 60 minutes. The evaluator also interviewed 3 senior living staff members (the executive director, the social worker, the Memory Fitness Lead who recruited the participants and served as the OTHC “community champion”), the OTHC facilitator, and the OTHC volunteer; these interviews lasted between 20 to 35 minutes. See Table 3.3 for demographics information of the process evaluation participants.

Table 3.3. Demographics of Process Evaluation Participants

<b>OTHC completers (n=7)</b>		<b>Retirement Community Staff (n= 3) OTHC group facilitator (n= 1) OTHC volunteer (n= 1)</b>	
<b>Sex</b>	3 females; 4 males	<b>Sex</b>	4 females; 1 male
<b>Age</b>	Mean: 77.6 (Range: 69 – 87)	<b>Age</b>	Mean: 46.6 (Range: 36 – 64)
<b>Race/ Ethnicity</b>	Caucasian: 5 Asian/Pacific Islander: 2	<b>Race/ Ethnicity</b>	Caucasian: 5

### 3.2 PROGRAM FIDELITY

OTHC is designed in a way that allow flexibility of the facilitator to tailor the weekly workshop activities to fit the specific DFCs group project chosen by each cycle of the OTHC participants. Additionally, the facilitator can adjust or omit certain planned activities impromptu to better fit the needs of the program participants (e.g. needs for more group discussion time, needs for longer time to process and respond to a question, etc.), but still address all program theory elements intended for the week. See Table 2.2. Spring 2017 OTHC Weekly Workshop Outline for the theory elements intended for each week.

Even though the program fidelity was evaluated based on whether all program theory elements planned for the week were addressed, the evaluator also kept notes of any observed deviations from the weekly workshop session plans and discussed these deviations with the OTHC group facilitator after each week's workshop. In Week 1, one of the activities, "Create team flag/banner," was omitted because this activity would require the participants to get up and walk around. Since many participants had a walker and the walkway was narrow in the activity room where the program was implemented, the OTHC facilitator decided to omit this activity. Additionally, one of the activities planned for Week 6, "Review design for guide" ("guide" refers to the memory-friendly tips put together by the participants), was moved to Week 7 because the participants had an upcoming group presentation (part of their DFCs project) scheduled 6 days from Week 6's workshop and the facilitator wanted to allow participants more time to rehearse their group presentation. Finally, the group agreements were not reviewed during two of the workshops. Since this cycle of the OTHC participants already knew each other beforehand, the OTHC facilitator decided that it was not necessary to review the group agreements every single

week. Despite these adjustments, all program theory elements intended for each week were addressed by the facilitator (program fidelity maintained).

### 3.3 DID OTHC ACHIEVE ITS PRIMARY PROGRAM OBJECTIVE, “TO PROVIDE AN ACCESSIBLE, MEANINGFUL, AND SUCCESSFUL OPPORTUNITY FOR PEOPLE LIVING WITH MEMORY LOSS TO DESIGN AND COMPLETE A DFCs PROJECT?”

The primary program objective of OTHC was achieved within the 8-week program duration. The OTHC participants chose their senior living community as their DFCs project’s target geographical community. In Week 2, OTHC participants established the objective of their community action project: “We exist in order to help people at [the name of the senior living community] know how to maintain or build relationships with people with memory loss.” In Week 3, OTHC participants decided that for their community action project, they would “create a short guide for interacting with neighbors with memory loss, and host a group discussion about it.” In Week 4, OTHC participants decided that they wanted to present their tips of interacting with people with memory loss during the first of a series of three memory loss-related talks given by the senior living community social worker. In Week 6, OTHC participants finalized their guide, deciding to include only the top seven tips from all tips that they generated from their homework assignments and discussions in weekly workshops. In Week 7, OTHC participants gave the group presentation at their senior living community; each OTHC participant shared one tip with the audience. After the group presentation, OTHC participants brainstormed ways to distribute their guide of 7 tips. In Week 8, after consulting the senior living community staff, OTHC participants decided to distribute their guide using the following media:

- Community newsletter (“tip of the month”)
- New resident’s handbook

- Community’s internal TV channel (“tip of the day”)
- Bookmarks (see Appendix H)
- Back of the cafeteria menu

### 3.4 HOW DID OTHC PARTICIPANTS PERCEIVE THEIR GROUP DFCS PROJECT (MEDIATORS)?

All OTHC completers agreed that they had met their group objective and agreed that the group presentation was a success. The main themes of OTHC completers’ perception of their group project were (1) *well-received by the senior living community*, (2) *exceeded expectations*, (3) *a sense of pride*, and (4) *I could not have done this without the group*. For example, Participant G stated, “Well, it was interesting because after it was over, friends or people I knew who were in the audience came up and spoke to me about the program, and it was so positive.”

Participant E said,

“People were, um, we were expecting four people to come, and there were 30 at least. Um, and people (the audience) looked very interested and offered their own, um, take on what we were talking about, and kind of were able to fill part of the discussion. I was really surprised and pleased with it.”

Participant A stated, “I have to say that I was very proud of the group and how everybody got up there and let their feelings, or their statement, or whatever be known.” Participant C stated,

“I think that um, it demonstrates how a group effort, you know, you have people who are concerned about, um, the problem, and they don’t know how to solve the problem, right? And you get together, and little by little that you contribute your effort. And it kind of – the ability of the group is greater than the individual, um, participating. So, every one of us couldn’t do what we did, right? But we did do [it] little by little, you know.”  
(Participant C)

OTHC staff and senior living staff also commented on OTHC completers’ sense of pride and the positive responses from the audience. For example, The OTHC facilitator commented,

“I would say, especially – I mean, so, from their reporting on the last day and when we debriefed the presentation, I felt like people took a lot of pride and especially the presentation, I’m feeling, like they were up there in front of all these people, they each had their own thing to say, they got positive feedback, some of them said afterwards people came up and said, “*Good job, that was great.*” So, I noticed a sense of pride in what they had accomplished specifically with their presentation.”

The senior living social worker stated,

“It was a group which I commend you all on that, um, through like, it developed a pride to be a part of and um, which I think can be challenging particularly with the topic.... I think it was so exciting that they were able come and present at one of the talks, um, because I think it did create quite a little buzz and excitement with the residents in general. And then I think the bookmarks, I think those are still kind of coming with the, you know – so I think, um, we’ll also see that positive message coming out in an informal way. But I, um, also see one of the positives, just in that talk and the residents sharing that, um, I was kind of amazed at how a couple of them were able to go from maybe feeling a little insecure about being identified to actually sharing their story and talking. (Chuckles.) It’s like that is safety and that’s what makes an impact on I think other residents because again it’s like, “*Oh you said, not one of us is going to be left behind*” and “*Oh, you said, you were depressed but* – “and so we again have this conversation that everyone craves to have.”

### 3.5 WHAT WAS THE OVERALL IMPRESSION OR OVERALL EXPERIENCE OF OTHC FROM THE PERSPECTIVES OF OTHC PARTICIPANTS, SENIOR LIVING STAFF, AND OTHC STAFF?

Thematic analysis revealed four main themes related to the overall experience or the overall impression of OTHC: (1) *a positive experience overall*, (2) *from initial confusion to “I’m glad I did it!”*, (3) *a cohesive group made up of the right mixture of people*, and (4) *successful participant recruitment and retention*.

#### 3.5.1 *A Positive Experience Overall*

All OTHC completers spoke positively about their overall experience of OTHC. They described their experience as *good, great, enjoyable, rewarding, meaningful, stimulating*, and/or *interesting*. For example, Participant A stated, “Oh, it was very enjoyable. I um, I was pleased with how the

group came together and um, worked so well give and take. And it was— it was a very rewarding experience.” Participant B stated, “It was a great experience. I thought everybody came together really well to, uh, set out what we, uh, decided to do finally.” Participant D stated, “I enjoyed the group. It was good. It was stimulating.” Participant E commented, “Um, it was an interesting and positive experience.” Participant G stated,

“I found it very meaningful to me and um, I don’t know that anything’ll come, but it’s nice to know that there are things that can be done [to address memory-related issues in the community] .... I enjoyed my time with the group.”

Similarly, all OTHC staff and senior living staff commented that they felt the program went well and believed that the participants enjoyed the experience. For example, the OTHC facilitator commented, “What is my impression of it? Um. (Laughs) I thought it went really well.” The OTHC volunteer stated, “I got the impression that everyone was really happy with the experience,” and that,

“I personally think with memory loss that even if you don’t remember the whole process, if you had a good experience in the, in the now, at the time, then that’s, that’s a win too. I mean even if they don’t remember it in, in six months from now.”

The senior living social worker commented, “My impression of the “Our Time has come”—. Um, my impression was, um, a group that came together and I was excited that residents were willing to participate and then, I think it exceeded anything I could have imagined.” The senior living executive director stated, “From our perspective, you know, the residents really enjoyed it. The staff enjoyed it. It seemed very successful.”

### 3.5.2 *From Initial Confusion to “I’m Glad I Did It!”*

Despite the overall positive experience and positive impression of OTHC, many interviewees pointed out that there was some initial confusion around the program purpose and the DFCs

project. Most of the OTHC completers initially thought OTHC was a program to help them deal with their own memory loss rather than to carry out a group project to improve their community. For example, Participant F stated, “That was, um, kind of misleading from the verbiage describing what was going to happen. Um, what happened was fine, but it wasn’t what I was expecting to have a personal response to.” The OTHC volunteer also commented,

“I did know that, that it was focused more on a community outreach and, and not as much like in a reflection on, on, on your, you know, what memory loss means to the individual participating in the, in the, the program. But yeah, what we were going to do as far as the project— I was like, ‘*Um, I have no idea.*’ (Chuckles)... There was that low in the middle point. I meant to say that after the third meeting (the week the group decided on their project), I felt like we were a little bit more grounded. We had an idea of what—, everyone had an idea of what was going on and what we were supposed to be doing, but I felt up to that point, there were a lot of blank faces and a lot of confusion.”

In addition, there was some uncertainty around OTHC participants’ self-identification as people with memory loss. The OTHC facilitator mentioned,

“In the beginning, some of the participants didn’t really necessarily seem to associate themselves with having memory loss, although – yeah, I think they all – would say they do, but in the beginning, it’s hard to tell, that they were talking a lot about *other people who have memory loss*”.

The senior living executive director also commented,

“Um, I think our group, um, the feedback I received, uh, from the staff at least is that maybe some of the members, al—, although we reached out and asked for individuals who identify with having some early memory loss, I really think that they really more identified with helping others and may not have personally gone down the road, uh, very far of identifying with their own memory loss.”

Despite the initial confusion and uncertainty, all OTHC completers stated that they were satisfied with the program and that they were glad that they stayed throughout the program:

(In the focus group) Evaluation: “So, even though it’s probably different from your original expectation, overall how satisfied are you with the program? Do you feel pretty satisfied, or—?” Focus group attendees: “Sure Yes.” “Very satisfied.” “Very satisfied.” “I thought it was a good group. It’s a good experience.”

“I thought it was going to be the same as the other programs. And then I stuck around, I said, ‘*Well, let’s see how this goes.*’ And so it was unclear as to how it’s going to evolve. I’m glad that I stuck it out.” (Participant C)

“It was an excellent thing to do. It, um, wasn’t what I expected but it was really — I’m really good I did — glad I did it.” (Participant E)

“Well, I think everybody was honest on the panel [focus group] because they said, ‘*This was not what we expected from this.*’ But— Oh yes, we’re happy with what we got. I think all of us, yes.” (Participant B)

### 3.5.3 *A Cohesive Group Made Up of the Right Mixture of People*

Many interviewees pointed out that it was the right mixture of people who attended the program, and they saw OTHC participants forming a cohesive working group. For example, Participant A stated, “A lot of people can’t sit down in a group and exchange ideas and get along, obviously. But— we did.” Participant G stated, “I don’t know who, who – how the [OTHC participants’] names were picked, but if I was picking a group to run something that I thought was important here, those would be the people that I would pick.” The senior living community champion said, “It was fun to watch the group come together as a cohesive whole and then to watch them develop a group, and really be excited about what they were producing.” The senior living executive director commented, “I think we were lucky in that sense that seems like we found some kind of the perfect match of those that participated.” The OTHC facilitator said, “the group really gelled well together and decided, um, on a project, came to decisions well together and then implemented it. And, um, yeah, I felt like, it was successful,” and later added, “...this group, yeah, some of them already have dinner together every day or whatever.... I didn’t have to spend—. I didn’t feel the need to spend as much time on trying to build a sense of group, um, cohesion.”

### 3.5.4 *Successful Participant Recruitment and Retention*

Senior living staff also pointed out that their residents filled up all 10 available spots of OTHC quickly and the program had a higher retention rate than their other programs. For example, the executive director commented,

“You know in here at [the name of the senior living community], we, sometimes we struggle with people who, um, can’t commit to an, like ongoing-, you know, they come to the first class, or the first and second, and they either lose interest or forget or you know and kind of what we do to kind of maintain that momentum and so it was really one of the first times that—, because I believe the max was 10 or 12 people, and we had that many people that, that signed up [for OTHC], um, and so we didn’t have to go out at that point and really recruit any new, any new participants. We had a list of people that we were going to reach out to if we had needed to, but we didn’t need to. Um, so I thought it was very interesting that that many [people signed up], and, and I know they didn’t all stick with the program to the whole thing, but a larger percentage than we’ve ever had before, um, stuck with the whole, the whole series. And, and just knowing a couple of the participants in there, um, two in particular, that had a lot of other kind of things going on in life and health and, um, and maybe previously would have stopped going, um, continue to go and they both, they both were people who in general I think have that greater satisfaction when they’re advocating for others and so I think that kind of resonated with them and gave them reason to continue to go.”

The senior living social worker echoed,

“While I wasn’t sitting in there, the outcome would not have been what it was if the three of you [OTHC staff and evaluator] weren’t skilled at helping them to find their voices and identity and kind of focus and, and making it engaging enough, because I also know retired, people who are retired, aren’t going to sit around a lot if they feel bored or, uh, like something is not meaningful and that you kept these people engaged through the whole process and excited.”

## 3.6 HOW ACCESSIBLE WAS OTHC (IMMEDIATE OUTCOME)?

As far as program accessibility was concerned, thematic analysis results revealed four main themes: (1) *the right amount of support and stimulation*; (2) *we liked the overall program duration but we needed a break during each weekly workshop*; (3) *appropriate and useful workshop activities*; and (4) *sufficient and flexible homework assignments promoted independence, a sense of responsibility, and commitment*.

### 3.6.1 *The Right Amount of Support and Stimulation*

All OTHC completers agreed that the OTHC facilitator was supportive of them and that their opinions were heard. They credited the OTHC facilitator's personality (e.g. a sense of humor, enthusiasm, etc.) and her effective group facilitating skills for making the program accessible—i.e. inclusive/non-judgmental, welcoming, contributable. For example, Participant B stated, “She [the OTHC facilitator] never gave an opinion on whether that was a good idea or not.”

Participant D stated, “I think she was very good. Yeah. She kept us moving. She kept it humorous.” Participant F stated, “A few small things, which I can't remember now, but I know it was enough to keep me involved and showing up again.” Participant G stated, “I felt that if you had an opinion it was always welcome.” Participant A stated,

“I think she was good.... She's very organized. I mean, almost over the top organized.... But I thought she was good. She was supportive. She was— She was um, very enthusiastic. She um, really wanted to do what she'd been asked to do and, and um, wanted to reward the, the classmate, the classmate, the class participants (OTHC participants) that they were on the right track and they were doing a good job and that that was a great idea. And, ‘*Oh wow. We'll have to keep—*’ and she'd make the little notes and keep things to the side and probably try to bring them in later, and work each respondent's ideas into the whole, the whole program. Whereas you can just say, ‘*Oh, yeah, that's a great idea*’ and then keep on going, just kind of like, ‘*Okay, I've acknowledged it. Now we can move on.*’ But it was more like, ‘*Okay, I've acknowledged it. Here she saw me write it down and I'll come back to that and we'll move on. But then when it's more appropriate to bring it in and talk about it, we'll bring it back.*’”

The senior living executive director also shared a similar observation,

“I think [the OTHC facilitator] and the people who're leading it were very engaging and, and personable, and I think that really helps. Um. And I think really it's, it's not a, um. (Pause.) The residents for my take away I guess, the residents, it, it wasn't patronizing, you know it wasn't talking down, it wasn't going through the motions that they really were doing instrumental, thought-provoking, you know, conversation, and, and they really look for that conversation and that contribution....”

### 3.6.2 *We Liked the Overall Program Duration but We Needed a Break during Each Weekly Workshop*

All OTHC completers agreed that the 8-week timeframe was just right. For example, Participant B stated, “Well, I got exactly what I expected there, as far as timeline was concerned.”

Participant D states, “If it’s going to be like a really long program for like 4 months, 6 months, maybe you would start to lose interest, but it was just 8 weeks, so it’s great.” Participant F stated, “Well, in order to accomplish the goals, that was sufficient and necessary. I wouldn’t want to keep it going for 16 weeks just to, to do something else.” Participant A commented,

“And I think it was about the right amount of time because um, another week would’ve just added more back patting, or, I don’t know. I don’t think we could’ve been any better prepared. We had everybody working really well together, and making things, and finding the resources needed to complete the task. And I think, I think it was about right.”

Considering the 2-hour weekly workshop duration, all OTHC participants thought it worked out for this program, but some also stressed the importance of having breaks in the middle. For example, Participant A stated, “I like the two hours.” Participant D commented, “Well, I think we got a lot done in every two hours. Uh, I think any more it might have gotten a little boring.” Participant F stated, “Two hours worked well. [The OTHC facilitator] kept the things going. There weren’t any blank spaces where you’re just sitting there wondering what’s going to happen next. So, two hours was not too much for this program.” Participant B said, “Two hours is fine if we have a break... in the middle to stand up and walk around if we need to, to do whatever necessary.” Participant E commented,

“It [the 2-hour session] was, it was hard and I notice other people sort of needing that break. I needed the break. I needed the break. I don’t want to miss anything and the two hours— once we started having the breaks regularly and we can depend on it, I felt better about it.” (Participant E)

The senior living social worker and the OTHC facilitator also commented on the importance of breaks:

“I felt like the eight weeks was good. I felt like the two hours— seemed fine. I know that there was one person that couldn’t sit that long, um, but yeah, having a break in the middle, to me it seemed like it was okay.” (OTHC facilitator)

“In the very beginning I heard complaints of, that they weren’t having breaks, but I sensed you all addressed that. I never heard that complaint after the first couple of groups.” (Senior living social worker)

### 3.6.3 *Appropriate and Useful Workshop Activities*

As far as program activities were concerned, all OTHC completers thought the pace, content, and the difficulty level were appropriate. They did not think anything—activity or content-wise—needed to be changed:

“It was good. Flowed well. [The OTHC facilitator] kept things going on track.”  
(Participant F)

“I was really pleased with the way all of them went.” (Participant G)

Evaluator: “So it was not too hard, or too fast, or too easy, or too slow?” Participant E: “Um, [The OTHC facilitator] is a very gifted facilitator and she was sensitive to us sort of sinking into confusion and co— and chaos and would kind of lead us out and whenever we got that sort of ‘Oh, gosh, what now?’ She would lead us out. She was good. She was really good.”

Evaluator: “Is there anything, like, activity-wise, or content-wise that could be improved?” Participant A: “Um. Boy, that’s the part I’m not good at. Um, what could be improved?” Evaluator: “Uh-hum.” Participant A: “Okay. I think for a program like this or a, or a class, a task like this. I don’t think so.”

“Uh no. There’s nothing I would change. I just, uh, for my own personal case, I don’t know what I would draw out for me. Uh, it’s all very helpful.” (Participant D)

In contrast, the OTHC volunteer suggested that the program spend more time on activities that help familiarize participants with one another in the future,

“Um, and maybe another session or some more time focused on getting to know everyone, getting the group getting to know each other . . . Like we did the, everybody took a rock and then why (an activity that each participant took a rock that represented them and then talked about why they chose the specific rock). You know that was great, I think, but I think maybe one more, or even two more activities like that to just, to just sort

of bring everybody together a little earlier would have been nice to just get the comfortability level down.”

Considering the program continuity, OTHC completers who had missed at least one session felt that they had no difficulty catching up with the group when they came back. They thought encouraging the person to come, a brief review of the previous week(s), and/or talking to other residents in the group were sufficient to keep them in the loop:

“Well, I missed the one session which I had to. Um. I didn’t feel like I—. [The OTHC facilitator] tends to go back over what was done the last time so I didn’t feel like I missed anything.” (Participant B)

“Encourage the person to, you know, well, come, you know, see what happens, right? And once they, they, the gap gets filled in, you know. I missed one group, um, space, um, I was kind of, ‘*Well, let’s go.*’” And I went, you know, and pretty soon, I knew what happened, um, a week before.” (Participant C)

“Um, I don’t know. [The OTHC facilitator] provided a summary each week when we got back together and that seemed to be enough.” (Participant F)

“You can always find other people in the group and stop them and ask them what happened.” (Participant G)

#### 3.6.4 *Sufficient and Flexible Homework Assignments Promoted Independence and Commitment*

Even though not all OTHC participants remembered the content of their homework assignment, their impression was that it was sufficient, flexible (participants could choose what they wanted to do as their homework assignment and how much effort they wanted to put in it), and not too difficult. For example, Participant C stated, “I think that was an interesting assignment because there were people who took the assignment seriously and people who didn’t.” Participant D stated, “I can’t remember what they gave us for homework. (Laughs.) So it must have not been too hard. (Laughs). Participant F stated,

“Um. I don’t know that I had much to do. Um. And none of them or any of them were of any imposition, or we didn’t have to stay up late and study, or any of that sort of stuff. So, it was sufficient to participant and keep the, um, momentum going.”

One participant pointed out that the homework assignment promoted independence in them,

“And not a lot, just something to give them a little independence, so that they can express their own independence rather than having to sit there every week and depend on somebody else to come up with the ideas, you know.”

Similarly, the senior living executive director felt that the homework assignment promoted a sense of responsibility and commitment in OTHC participants,

“I think they really enjoyed [the homework assignment]. If not, was a little added healthy stress of having sort of their homework, or the pieces that they had to go and they were accountable to bring back to the group. I mean I think, um, that added another layer of responsibility and commitment to the project into the group.”

### 3.7 INTERMEDIATE OUTCOME: OTHC PARTICIPANTS’ SENSE OF PURPOSE

Thematic analysis results suggested that there were two main themes related to OTHC participants’ sense of purpose: (1) *a positive influence on my sense of purpose* and (2) *I don’t know/it’s temporary*.

#### 3.7.1 *A Positive Influence on My Sense of Purpose*

The majority of the OTHC completers expressed that the program influenced their sense of purpose positively. Two of them thought that the program influenced their sense of purpose through giving them a good cause to be fully committed to:

“I was optimistic because, from my point of view, um, I was going through life.... And for once in my life, I’m— as— I’m committed to do the best I can, right?” (Participant C)

“I think it did [influence my sense of purpose], because it was— I felt like we had to make a good effort because it was a good cause. So, in that respect it influenced me.” (Participant G)

One felt the program supported her sense of purpose because it matched her core values:

Evaluator: "... I want to know how the program influenced you as a person, for example, how did the program influence your sense of purpose?" Participant E: "It was very — for me trying to help other folks is important. Umm. It's actually one of my core values that I learned from my mother when I was a little person. Umm. It also gave me something to say to people who more or less imagined that I jumped down a hole and I was in a nursing home and drugged out of my mind when you know, I tell my friends — and I moved in this retirement facility and I go, 'Oh, poor you.' 'No, not poor me.' Um. And so I'd say, 'and we worked on a project, so we're not just passive.' And um. I'm very hopeful about the volunteer coordinator." Evaluator: "Uh-hmm. So this program actually supports your sense of purpose?" Participant E: "Oh, yes." Evaluator: "And it matches your core value that you always have?" Participant E: "Yes."

One felt the program influenced his sense of purpose through opening his eyes to memory loss-related issues:

"Yeah, I find... I — since that class, and during the class, I find myself being more attuned to people with memory loss and trying to find out how can I — how can I work with them better, how can I apply one of our seven— principles." (Participant A)

### 3.7.2 *I Don't Know/It's Temporary*

Among the remaining OTHC completers, two said that they did not know if the program had influenced their sense of purpose ("Uh, I don't know exactly."), while one stated that the program gave him a sense of purpose but only for the time being ("Well, it didn't influence. It just gave me a little sense of purpose for a little while.").

Even though some OTHC completers stated that they were uncertain if the program influenced their sense of purpose, the senior living executive director commented that as a group, she felt the program had affected their sense of purpose:

"I think the most, the biggest change I've said-, I've seen I think is kind of what I said as far as the individuals that were involved in the project that I feel like they have a different and maybe it'll fade a little bit, um, but a different kind of sense of purpose and um, that they, you know contributed to this thing to make a better place for others."

### 3.8 INTERMEDIATE OUTCOME: OTHC PARTICIPANTS' SELF-ESTEEM

Two main themes related to OTHC participants' self-esteem were revealed: (1) *It helped my self-esteem* and (2) *no effect/I always have high self-esteem*.

#### 3.8.1 *It Helped My Self-Esteem*

Three OTHC completers believed that the program helped their self-esteem through accepting them into the group, giving them an opportunity to do something good, and giving them something to say to their friends:

“My esteem was maintained or even increased a little bit because I was – I was accepted in the group.” (Participant A)

“It made me feel better that I had finally done something that was overtly related to actually making something better, something we (participant and her husband) just had never done.” (Participant G)

“It helped. Uh, it definitely did help, and it also gave me something to say to my friends.” (Participant E)

One did not disagree that the program had influenced his self-esteem, but he also felt it was hard to answer this question:

Evaluator: “And how did the program influence your overall self-esteem?” Participant D: “Well, that’s, that’s a tough one to answer. I don’t think it didn’t— what’s the word I want? (Pause.) It, just—.” (Participant laughed and then paused for a few seconds.)  
Evaluator: “It’s hard to think about this one?” Participant D: “Yeah.”

#### 3.8.2 *No Effect/I Always Have High Self-Esteem*

Among the remaining OTHC completers, two said the program did not influence their self-esteem (“I don’t think it did.”), while one stated that he always had high self-esteem:

“Well, I’m kind of – kind of invulnerable to my self-esteem. I – you know, I’m arrogant enough, so – yeah. (Laughs.) You know, to not be harmed by self-esteem si-, situation, you know. (Participant C)

### 3.9 INTERMEDIATE OUTCOME: OTHC PARTICIPANTS' GENERAL SELF-EFFICACY

Two main themes related to OTHC participants' general self-efficacy were identified: (1) *I gained confidence in helping others in the future* and (2) *no difference/I always have high self-efficacy*.

#### 3.9.1 *I Gained Confidence in Helping Others in The Future*

When asked about their confidence in their ability to make a difference in life (general self-efficacy) after the program, most OTHC completers felt that they gained confidence in their ability to help others and became more aware of memory loss-related issues. For example, Participant B stated, "I think—as a group, I think we did [become more confident in helping others]." Participant G stated, "It probably— made me feel a little more confident about trying to help others." Participant A stated,

"Yeah, because no matter where I go from now on, or whatever setting I'm in, I'm always going to be evaluating where it fits in with memory, memory problems. And if I can help, If I can add something to the program, or express something in the group that will get them to thinking about something, um, and make them feel better about themselves"

#### 3.9.2 *No Difference/I Always Have High Self-Efficacy*

Two OTHC completers did not think the program had influenced their general self-efficacy. One simply said, "No difference," while the other stated that he had always been confident in his ability to make a difference:

Evaluator: "So you always believe you can make a difference, but it's—." Participant C: "Right. Right. I— When I was in school, somebody asked me, 'Well, do you believe in God?' 'No, I don't.' 'Okay. Well, what do you believe in?' 'Let me think about that.' Then I thought about it, came back to him, 'This I believe. I believe that I am not living my life in futility, right? I can make a difference.'"

### 3.10 INTERMEDIATE OUTCOME: OTHC PARTICIPANTS' COMMUNITY SERVICES SELF-EFFICACY

The predominant theme of OTHC participants' community services self-efficacy was "*I feel positive, but it depends*". When asked about their confidence in making their senior living community a better place for people with memory loss (community services self-efficacy) after the program, nearly all OTHC completers expressed that they felt positive about the idea, but some also pointed out that it would take some time and would depend on the people who continue the efforts after the program. For example, Participant A stated, "Oh, absolutely, that it can be done, that we did do it." Participant C stated, "I'll persist." Participant E stated, "We can make some difference you know. It takes—, everything, in my experience that everything takes a while, and I think the people in the group interacting with other residents may have a ripple effect." Participant G stated, "I think it would depend on what the people who continue with this program do." On the other hand, one OTHC completer revealed that making his senior living community a better place was not his priority ("Um. I don't know that making [the name of the senior living community] a better place is high on my list of the things to accomplish.")

### 3.11 INTERMEDIATE OUTCOME: OTHC PARTICIPANTS' CONNECTION TO OTHER GROUP MEMBERS

All OTHC completers agreed that the program had positive impacts on their sense of connection to the other group members. The main themes were (1) *we learned a little more about each other* and (2) *it is easier to interact with them now*. For example, Participant B said, "Oh, definitely yes. I enjoyed them." Participant C said, "I think that we have made connection to the people in the group. I think it was positive. Right? I knew everybody, but I didn't know anybody, you know. I knew— everybody just a little bit more, right?" Participant D stated, "A little bit more, yeah, it's

just that, uh—. I don't feel like I'm interrupting whatever they're doing if I came up to them and talked to them for a few minutes.” Participant F commented,

“It made it easier to talk to them, um, knowing a little bit more about their backgrounds, and um, experiences, and stuff. They aren't a group where I want to promote, you know, bridge games, or um, or work parties, or any of that sort of thing. But it's easier, it's nice to say, 'Hi' in the hall to um, '[Participant E's name]', as opposed to just say 'Hi you', or whatever.” (Participant F)

Additionally, two participants who considered themselves as “followers” or “non-joiners” pointed out that they appreciated that OTHC exposed them to different personalities, giving them an opportunity to work with residents who were “leaders” and “who run the show around here”, that they otherwise would not have had the opportunity to. For example, Participant D stated,

“It was interesting the fact that there were so many people from our area here that were interested and took part and some of them were leaders and some of them were followers and those came out quite clearly who was who.’

Participant G stated, “So, when I first came in and I saw all the people that were there, I'm thinking to myself, *‘What are we doing here?’*” Because we don't – or are normally not joiners.” and later added,

“What I found was if you, if you do work with those kinds of people [(the leaders)], you get a different kind of experience and so everybody should, they should mix it, mix it, because it really helps the overall participation.” (Participant G)

The OTHC Facilitator also felt that the program may have helped OTHC participants feel more comfortable with each other: “My guess is that it helps some people feel a little bit more comfortable, um, with what they were dealing with, with memory. Um. A little bit more –, yeah, comfortable, a little bit more connected with others.”

### 3.12 OTHC PARTICIPANTS' CONNECTION TO OTHER RESIDENTS AT THE SENIOR LIVING COMMUNITY

The main themes related to OTHC participants' connection to other residents at their senior living community were (1) *I saw positive influences* and (2) *I am not sure*.

#### 3.12.1 *I Saw Positive Influences*

Most OTHC completers mentioned positive influences of the program on their connection with other residents. Two OTHC completers stated that people were appreciative of what they did (“Yes. They came and thanked us.”), one felt people showed interest in their group (“People would come up to us and ask us what we were doing in our, in our group.”), one simply stated that “I think it was good,” and one felt she became more mindful of how her own behaviors might influence others in the senior living community,

“It made me be more, um, attentive to my behavior, um, because you know there are a lot of people who don't hear very well. There are a lot of people who have moments of not being able to find a word and not being able to remember what just happened and those sorts of things.” (Participant E)

One of those who mentioned positive influences also pointed out the mutuality in this process (the helper vs. the helped), “You found something that was, that was enjoyable, as well as—. I mean, not just enjoyable for you, but enjoyable to you, but beneficial to someone else [other residents in the community], which is kind of a *double enjoyable*.” (Participant A)

The senior living social worker also shared a similar observation,

“I think it is, um – you know, in social work, there's a social worker Perlman who says in her text, you know, ‘*A good relationship, a therapeutic relationship leaves both people changed*’ and I think this group was an example of that, nobody walked away without having some impact and something that made life better I think. They don't get to say that often with programs or services.”

### 3.12.2 *I Am Not Sure*

On the contrary, two OTHC completers were not sure if the program had influenced their connection to other residents at their senior living community. One stated, “I’m not sure it had any influence.” The other felt it was too early to tell (“They remain to be seen.”).

## 3.13 SENIOR-LIVING BASED FACILITATORS AND BARRIERS

Thematic analysis revealed seven main themes relevant to experienced or anticipated senior living-based facilitators to implement OTHC, from the perspective of interviewees: (1) *leadership involvement and staff buy-in*, (2) *a receptive community culture* (i.e. senior living community owners’ value of providing best services for aging in place, concurrent community events around memory loss, on-going publicity of OTHC within the senior living community), (3) *strategies that promote program attendance* (i.e. reminders, having a familiar face, refreshments), (4) *participants living on site*, (5) *participants knowing and incorporating their staff and available resources in the community*, (6) *adequate planning before program implementation*, and (7) *(staff knowledge of) participant characteristics*. For supporting quotes, see Appendix I.

Main themes of experienced or anticipated barriers to implement OTHC in a senior living community setting include: (1) *residents’ negative preconception of memory loss and relevant programs*; (2) *residents’ (in)ability to participate* (e.g. physical health, cognitive capacity, etc.); (3) *inadequate advertisement of the program*; (4) *a lack of staff understanding about the program or close-minded leaders*; and (5) *competing with other programs for time and space*. For supporting quotes, see Appendix J.

## 3.14 ADDITIONAL BENEFITS OF OTHC

Three additional themes relevant to benefits of OTHC from the perspectives of OTHC

staff and senior living staff were revealed: (1) *an opportunity to help, stay engaged, and be autonomous*, (2) *destigmatizing and awareness raising*, and (3) *community building and lasting impact*. See Appendix K.

OTHC staff and senior living staff did not observe any negative effects of OTHC. For example, the OTHC volunteer said, “I think that what we talked about before, there were some definite um, changes that can be made. Um, but I don’t think that anyone was, was offended or, or any, affected negatively by the program at all.” The senior living social worker stated, “I think, I was aware one woman, um, maybe dropped out, which is to happen, um, and – uh, but that’s not a negative effect of the program.” The senior living community champion stated,

“I didn’t notice any negative effects. The only negative I might say is the two participants who had to quit because of physical issues were actually very disappointed to quit. They didn’t really want to, but they felt like they had to. But, I mean, that’s just the way it is.”

### 3.15 RECOMMENDATIONS

Several interviewees provided recommendations for the program. The predominant theme is *clearer communication of program purpose*. For example, Participant B suggested, “Um, in the beginning, um, when we were signing up for the program, maybe a little more clarity in exactly what, uh, we were going to do because we didn’t get what we expected.” The OTHC facilitator commented,

“I think the –, just that piece about – (Laughs), a lot of the participants didn’t know what they were signing up for, is interesting. I don’t really know what to do with that, but um, yeah, I’m hoping that I can be more clear in the future when I’m advertising it.”

The OTHC volunteer stated, “... it’s really just being, uh, more clear that it is not a program to .... It’s not a program solely to help you deal with your own memory loss. It’s, it’s more of a community awareness program,” and then added, “I think having some more solidified ideas to get that, to get at least the ball rolling on them coming up with ideas is, is really smart.”

## Chapter 4. DISCUSSION AND CONCLUSION

This process evaluation revealed that even though it was the first time OTHC was implemented in a senior living community setting, the program was successfully implemented and was well-received by both OTHC participants and senior living staff. All interviewees expressed that they had a positive experience with this cycle of OTHC. All OTHC completers expressed that (1) they felt the OTHC facilitator was supportive to them, (2) they felt their opinions were heard, (3) they thought the program duration, the workshop duration (with breaks in the middle), and weekly activities were appropriate for this program, (4) they agreed that their group project was a success and were proud of what they had accomplished, and (5) they were very satisfied with the program, despite the initial confusion regarding the program purpose. The program achieved its primary objective, “to provide an accessible, meaningful, and successful opportunity for people with memory loss to design and complete a DFCs project.” The program also achieved its immediate program outcome—perceived program accessibility—in all OTHC completers. The positive responses from staff and residents in the hosting senior living community towards the DFCs project carried out by the OTHC participants, as well as conversations between senior living staff and OTHC participants regarding continuing this effort after the completion of OTHC showed that OTHC participants’ decision to choose their senior living community as their target community (instead of a wider geographical community such as Seattle City) may potentially lead to long-term positive impact of OTHC on their senior living community.

Considering the intermediate program outcomes—sense of purpose, self-esteem, self-efficacy, and sense of connection to the community, the process evaluation results showed that the program had mixed success. While most OTHC completers reported positive changes in their sense of purpose, self-esteem, self-efficacy, and sense of connection to the community after the

program completion, a few did not. This might be explained by participants' personal calling, ceiling effect, participants' success appraisal, and participants' interpretation of these concepts. For example, one participant revealed that even though he wanted to learn something about memory loss, it was not his priority to make his senior living community better for people with memory loss. He stayed throughout the program because the OTHC facilitator was engaging, the workshops were different enough from week to week, and he wanted to show his support of the community champion. Therefore, to him, it was an interesting and satisfying experience, but he did not think the program had changed his sense of purpose. One participant revealed that he always had high self-esteem and high self-efficacy, which left him little room to improve on these outcomes (ceiling effect). Several participants mentioned that even though they were proud of what they accomplished, they felt that they could not have done it without the group. Perceiving the success of their DFCs project as the result of a group effort rather than their individual success might explain why some participants did not generalize this experience to a personal level (e.g. self-esteem). Even though all OTHC completers felt that their DFCs project was well-received by the audience, two were not sure if the program had any effect on their sense of connection to other residents in the senior living community. A possible explanation is that OTHC participants tended to interpret the term "sense of connection" as their 1 to 1 connection with other senior living residents instead of a more general sense of belonging.

From the perspective of senior living staff, they noticed that the program affected OTHC completers' sense of purpose as a group; they also noticed OTHC participants had a sense of pride of their group. Additionally, senior living staff commented that having an opportunity to help, stay engaged, and be autonomous was a benefit to their residents by itself. Additionally, while this process evaluation focused on immediate program outcomes, mediators, and

intermediate program outcomes on a personal-level, the senior living staff brought up community-level benefits that they observed, such as destigmatizing, awareness-raising, and community-building. These potential community-level benefits of OTHC should be formally evaluated by the MBWC in the future.

This process evaluation identified potential senior living-based facilitators and barriers to implement OTHC, including community level factors (e.g. community culture), staff level factors (e.g. leadership involvement, staff understanding of the program, etc.), participant level factors (e.g. preconception of memory loss and relevant programs, knowledge of their community staff and resources, etc.), and logistics (reminders, refreshments, etc.). Most of these factors can be either facilitators or barriers. For example, staff understanding of the program is a facilitator while a lack of staff understanding of the program is a barrier. The MBWC should take these facilitators and barriers into account when implementing OTHC in senior living community settings in the future.

The main recommendation for the program from the interviewees was clearer communication of the program purpose. Since OTHC completers expressed that they realized the program purpose was different from their expectations during Week 1's workshop, the MBWC may consider including an information session of the program in the hosting senior living community in the future as part of the recruitment protocol to ensure potential participants understand what they sign up for. Another potential solution is to redesign the OTHC flyer with people with memory loss to ensure that the program purpose is communicated to them clearly. From the perspective of the OTHC volunteer, in contrast, he felt the initial confusion lasted until OTHC participants had decided on their DFCs project in Week 3. The OTHC volunteer felt it might be helpful to have several predetermined project options for participants to choose from

instead of leaving it completely open for the participants to decide. However, it is unknown whether limiting project options would take away a sense of ownership and autonomy from the participants, and whether these predetermined projects would be a good fit for the specific community that OTHC participants choose to intervene with.

#### 4.1 LIMITATIONS

There are several limitations of this process evaluation. First, participants who dropped out from the program were not interviewed. Second, even though some of the interview questions used in this process evaluation were modified from the interview questions used in Olsen et al's (2015) study with people with dementia, the evaluator did not pilot her interview guide and focus group guide with people with memory loss. Additionally, some of the concepts seem to be too abstract. For example, the evaluator noticed that it seemed to be easier for participants to self-evaluate whether they would do something (intention) instead of rating their confidence in their ability to do something (self-efficacy). Therefore, it would be important to pilot the interview questions and focus group questions with people with memory loss for future evaluations. Lastly, this process evaluation was conducted with only one cycle of OTHC in one senior living community. Some of the results may not be generalizable to other senior living communities.

#### 4.2 CONCLUSION

OTHC can be successfully implemented in a senior living community setting. OTHC achieved its primary program objective, to provide an accessible, meaningful, and successful opportunity for people with memory loss to design and complete a DFCs project. All OTHC completers, OTHC staff, and senior living staff had a positive overall experience of the program. All OTHC completers perceived the program as accessible (welcoming, inclusive, etc.) and were very

satisfied with the program. OTHC participants' individual differences, such as personal calling, success appraisal, interpretation of intermediate program outcomes, and ceiling effect are all potential factors that can affect the intermediate outcomes. The program should ensure that potential participants understand the program purpose at the time of enrollment.

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## APPENDIX A: OTHC FLYER

# Our Time Has Come!

An 8-week workshop series for Lakeshore residents  
with early stage memory loss



## Wednesdays

## 9:30-11:30 am

**March 1, 8, 15, 22**

**April 5, 12, 19, 26**

Do you want to make a difference in your community? Join other Lakeshore residents to develop a project that will help challenge stigma and build understanding about living with memory loss. This free workshop series is offered by the UW Memory & Brain Wellness Center and hosted by The Lakeshore.

Together, you will:

- Learn about advocacy projects completed by other people with memory loss around the world
- Explore your own stories and experience with memory loss
- Choose a project to help build understanding in your community
- Work together to make it happen

*"Our project surpassed my expectations.  
We all got together and made something beautiful happen."  
-Mary, participant from Summer 2016*

Registration deadline ---. To register or for more information,  
contact ----

UW MEDICINE | MEMORY & BRAIN WELLNESS CENTER

## APPENDIX B: OTHC FIDELITY CHECKLIST EXAMPLE

### OTHC Fidelity Checklist

Observer: \_\_\_\_\_ Date: \_\_\_\_\_

Facilitator Skills/Roles				
Facilitator behavior	Observed	Not Observed	Not Applicable	Comments
Holds attention of participants				
Clear transitions between sections of the agenda (e.g. Verbally reminding participants it is the end of an activity)				
Evidence of preparation (e.g. materials are ready for each activity; the group facilitator is organized; the group facilitator is familiar with the planned activities; etc.)				
Enthusiasm/energy				
Models respect and inclusion (e.g. providing opportunities for participants to respond individually, verbally acknowledging each participant's feedback/input, etc.)				
Welcomes each person by name				
Speaks clearly and projects voice				
Maintains eye contact				
Smooth hand-offs between different facilitators				
Holds group accountable to group agreements (e.g. The facilitator intervenes if one or more participants violate the agreements).				
Actively seeks ways to form group bonds (e.g. pointing out similarities between group members)				
<b>Demonstrates dementia-friendly practices, to include:</b>	<b>Observed</b>	<b>Not Observed</b>	<b>Not Applicable</b>	<b>Comments</b>
Short (one phrase) sentences				
Asks one question at a time				
Gives time for participants to process and respond				
Adapts questions or tasks as needed for each participant				

Uses gestures and facial expressions to reinforce ideas				
Notes on whiteboard during brainstorming or group planning				
Points to key areas on whiteboard to help participants know where to focus				
Avoid putting an individual on the spot to recall factual details, as evident by posting the question to the whole group/multiple individuals at the same time or by asking questions that are feeling-oriented (e.g. the participant's feeling about certain topics/experience) instead.				
Affirms varied ways of participating and responding (e.g. listing all participant responses on the white board without judging; acknowledging non-verbal responses such as smiling and nodding, etc.)				

<b>General Components for Each Session:</b>				
<b>Session Component</b>	<b>Implemented</b>	<b>Not implemented</b>	<b>Not Applicable</b>	<b>Comments</b>
Welcome				
Introduction of facilitator(s)				
Opening Ritual (Song)				
Review of program purpose and overall agenda				
Review of session goal(s)				
Review of group agreements				
Review homework from last week (if applicable)				
Individual, paired and group work				
Short break midway through				

Planning next steps				
Assigning homework (as needed)				
Review of what was accomplished				
Review group agreements and asking if any group behaviors need to be adjusted				
Preview of next week's agenda				
Closing Ritual (Song)				

### Session 2 Core Activities

- Review purpose of workshop series, and overall agenda
- Review group agreements
- Small group discussion: barriers & bridges to community
- Large group reflection on themes
- Voting on project focus
- Review of day
- Preview next week

### Overall Completion of Session Plan

- Implemented all activities in the session plan? Yes / No

Comments:

## APPENDIX C: OTHC SESSION PLAN EXAMPLE

### **Session 5: Working Together**

#### **Objectives:**

Participants will be able to...

- Report back on homework items
- Review tips on maintaining relationships with people with memory loss
- Decide top tips to include in guide
- Decide basic design for guide
- Create plan for how to present these tips at the Lakeshore presentation

#### **Summary of Activities:**

- Welcome
- Review daily goals, group agreements
- Remind about project, the action steps to complete the project, and what we accomplished last week
- Add to list of tips, by reviewing homework
- Choose top tips to use in guide
- Discuss graphic design for guide
- Discuss and decide ways to present the information
- Assign homework
- Review of the day, preview next week

#### **Materials Needed:**

- Feedback cards
- Folders
- Nametags
- Pens, Markers
- Poster Paper
- Water, Cups

## Our Time Has Come, Facilitator Guide

## Session 5

Time	Activity	Methods/Elements	Materials	Lead
9 – 9:30	<b>Set-Up</b> U-shaped tables; 14 chairs; water out		<ul style="list-style-type: none"> <li>• Tables, chairs</li> <li>• Water, cups</li> </ul>	
9:15 – 9:30	<b>Arrival</b> Distribute name tents. Serve water.		<ul style="list-style-type: none"> <li>• Name tents</li> <li>• Markers</li> </ul>	
9:30 – 9:35	<b>Welcome</b> <ul style="list-style-type: none"> <li>• Welcome to all (2)</li> <li>• Intro 'Our Time Has Come' and sing it (3)</li> </ul>	Multiple senses Daily rhythm <i>a) DF facilitation elements</i>	<ul style="list-style-type: none"> <li>• Song lyrics</li> </ul>	
9:35 – 9:40	<b>Review &amp; Session Intro</b> <ul style="list-style-type: none"> <li>• Review group name, group agreements, purpose</li> <li>• Introduce daily agenda/goals</li> </ul>	<i>a) DF facilitation elements</i> <i>c) setting group expectations</i> <i>e) goal setting</i>	<ul style="list-style-type: none"> <li>• Poster: Copy of agreements</li> <li>• Poster: Copy of daily goals</li> </ul>	
9:40 – 10:20	<b>Taking Action – Tips for Maintaining Relationships</b> <ul style="list-style-type: none"> <li>• Review project and action steps, and what we accomplished last week (5)</li> <li>• Report back on homework items (15). List each new tip on poster paper.</li> <li>• Post all the pages that show tips, including personal ones from last week. Discuss if there are any that can be combined. (5)</li> <li>• Cut each tip out so it can be moved around. (5)</li> <li>• Re-arrange the tips in order of preference. Decide how many we want to include (10)</li> <li>• Assign homework items as needed.</li> </ul>	Group discussion <i>p) consistent attention to the wider community (e.g. the retirement community or Seattle)</i> <i>m) validation of personal experience/input</i> <i>k) opportunity for choice, autonomy &amp; impact</i> <i>l) opportunity for leadership</i>	<ul style="list-style-type: none"> <li>• Notebooks</li> <li>• Poster: Copy of action steps</li> <li>• Whiteboard, markers</li> </ul>	
10:20 – 10:30	<b>Break</b>			
10:30 – 11:15	<b>Taking Action – Prep for Presentation</b> <ul style="list-style-type: none"> <li>• Pass out presentation descriptions.</li> <li>• Review previous ideas on presentation format, from poster paper (5)</li> <li>• 1 – 2 – 4 – ALL brainstorm about ways to present the information. (10)</li> <li>• Group discussion: Complete the 30 minute presentation agenda (on poster paper) (30). Assign roles as needed.</li> <li>• Assign homework items as needed.</li> </ul>	Group discussion <i>k) opportunity for choice, autonomy &amp; impact</i> <i>l) opportunity for leadership</i> <i>h) high expectations (expect you to succeed)</i> <i>q) opportunities to interact with others with memory loss.</i> <i>m) validation of personal experience/input</i>	<ul style="list-style-type: none"> <li>• Whiteboard, markers</li> <li>• Note paper</li> </ul>	
11:15 – 11:25	<b>Looking Back / Looking Ahead</b> <ul style="list-style-type: none"> <li>• Review the day – Goals met? Group agreements followed? Anything to improve how we work together next time?</li> <li>• Reinforce homework (if any).</li> <li>• Preview next week's goals.</li> <li>• Evaluation card (5)</li> </ul>	<i>a) DF facilitation elements</i> <i>g) evaluation of goal attainment</i> <i>e) goal setting</i>	<ul style="list-style-type: none"> <li>• Feedback cards</li> </ul>	
11:25 – 11:30	<b>Closing</b> <ul style="list-style-type: none"> <li>• Sing "Our Time Has Come"</li> </ul>	Daily rhythm (closing practice) <i>a) DF facilitation elements</i>	<ul style="list-style-type: none"> <li>• Song lyrics</li> </ul>	

## APPENDIX D: DEMOGRAPHIC FORM

1. Gender: Female  Male

2. Year of Birth: \_\_\_\_\_

3. Ethnic background: (Please check the box  below that applies to you.)

African American

Asian/Pacific Islander

Caucasian

Hispanic

Native American

Other: \_\_\_\_\_

4. I am a: (Please check the box  below that applies to you):

Our Time Has Come **participant**

Our Time Has Come **group facilitator**

Our Time Has Come **volunteer**

Retirement Community staff

Other: \_\_\_\_\_

## APPENDIX E: FOCUS GROUP GUIDE

- **What is your overall impression of the Our Time Has Come program?**

How well did the Our Time Has Come program meet your expectations?

How satisfied are you with the overall program?

Did you feel the group agreements help you understand what was expected of you in the group?  
(If not, what suggestions do you have for setting clear group expectations?)

- **Do you think you met your objective as a group? Why or why not?**

- **Do you feel that the group presentation was a success/well received?**

Did you receive the right amount of support from the Our Time Has Come program when you were preparing for your group presentation?

Is there anything the program could have done differently to better facilitate the process?

- **Have you noticed any positive changes around being memory-friendly in the [name of the senior living] since your presentation?**
- **What are some suggestions you have for the program to better support the next cycle of the Our Time Has Come participants?**

## **APPENDIX F: INDIVIDUAL INTERVIEW GUIDE**

### **Questions for OTHC participants:**

- How would you describe your experience being part of the Our Time Has Come program?
- What are some similarities and differences between Our Time Has Come and other programs that you have attended in the past?
- (Review weekly workshop activities with PowerPoint slides)
- What activities of the program that you found especially useful? What aspects of the program you enjoyed the most? Were there any activities that could be improved?
- How was the pace of the activities?
- How did it feel to meet 2 hours at a time?
- How was the 8-week time frame?
- How easy or hard was it for you to participate in every week's activities when you were in the program?
- How was your experience completing the homework assignments?
- How supportive was the group facilitators to you when you attended the program?
- Did you feel your opinions were heard? Why or why not?
- What would be something the program could do to help a participant catch up with the rest of the group after he or she has missed a session?
- How did the program influence your sense of purpose?
- How did the program influence your overall self-esteem?
- How did the program influence your confidence in making a difference in your life in general?
- How did the program influence your confidence in making [the name of the senior living community] a better place for people with memory loss? How do you feel about continuing your work to make [the name of the senior living community] more memory-friendly after the completion of the Our Time Has Come program?
- How did the program influence your sense of connection to others in the group?
- How did the program influence your sense of connection to residents at [the name of the senior living community] in general?
- Do you have any additional feedback for the program? Is there anything else you would like to say?

### **Questions for OTHC staff and senior living staff:**

- What is your impression of the Our Time Has Come program at the Lakeshore?
- What was your involvement with the OTHC program? What kind of support did you provide for the OTHC program/participants?
- How was your experience supporting the OTHC program/participants?
- Have you noticed any positive effects of the program on the participants? If so, what are they?
- Have you noticed any negative effects of the program on the participants? If so, what are they?
- In your opinion, what were some organizational or institutional factors that contributed to the success of this program at the Lakeshore?

- What are some potential barriers (observed or expected) should the program be aware of when it is implemented in a retirement community setting in general?
- Do you have any additional feedback or recommendations for the program?

## APPENDIX G: IRB DETERMINATION LETTER



### NOT RESEARCH

February 14, 2017

Dear Shih-yin Lin:

On February 14<sup>th</sup>, 2017 the University of Washington Human Subjects Division reviewed the following application:

Type of Review:	Initial Study
Title of Study:	Process Evaluation of "Our Time Has Come"--a Dementia-Friendly Communities Workshop
Investigator:	Shih-yin Lin
IRB ID:	STUDY00001235
Funding:	None
IND, IDE, or HDE:	None

The Human Subjects Division determined that the proposed activity is not research, as defined by federal and state regulations. Therefore, review and approval by the University of Washington IRB is not required.

This determination applies only to the activities described in this application.


If you consider changes to the activities in the future and know that the changes will require IRB review (or you are not certain), you may request a review or new determination by submitting a Modification to this application.

We wish you great success.

Sincerely,

Emily Guthrie  
UW HSD Assistant Director

## APPENDIX H: “TIPS FOR BEING A GOOD NEIGHBOR TO PEOPLE WITH MEMORY LOSS” BOOKMARKS



**Tips for being a good neighbor to people with memory loss:**

~

Wear your nametag.

Speak slowly, clearly, and be patient.

Recognize I'm not stupid.  
Being smart does not mean always remembering.

~

*Prepared by a group of Lakeshore residents, Spring 2017*



**Tips for being a good neighbor to people with memory loss:**

~

Treat me as someone with strengths.

If you need to tell me that I've forgotten something, tell me gently and with warmth.

~

*Prepared by a group of Lakeshore residents, Spring 2017*



**Tips for being a good neighbor to people with memory loss:**

~

Please talk to me directly  
- not through someone else.

When you ask a question  
- *ask it*. “I want to know what time it is, not how the clock is made.”

~

*Prepared by a group of Lakeshore residents, Spring 2017*

**Tips for being a good neighbor to people with memory loss:**

Wear your nametag.

Treat me as someone with strengths.

Speak slowly, clearly, and be patient.

Recognize I'm not stupid.  
Being smart does not mean always remembering.

If you need to tell me that I've forgotten something, tell me gently and with warmth.

Please talk to me directly  
- not through someone else!

When you ask a question  
- *ask it*. “I want to know what time it is, not how the clock is made.”

~

*Prepared by a group of Lakeshore residents, Spring 2017*

## APPENDIX I: SENIOR LIVING-BASED FACILITATORS TO IMPLEMENT OTHC: THEMES AND SUPPORTING QUOTES

Senior living – based facilitator themes <sup>a</sup>	Supporting Quotes	Notes
Leadership involvement and staff buy-in	<p>“The staff were on board and different layers of staff were on board and that happened through having a program champion, which was [the senior living community champion’s name]. Um. In the beginning, when I reached out to her, she was like, ‘<i>Yes, yes, yes, I’m so excited to have this here,</i>’ and she really made it happen. Like, she reached out to the executive director who was a little like, ‘<i>Mm- I don’t know, well, I need to know more about this,</i>’ and then I talked to the executive director and she again said, ‘<i>[The name of the senior living community champion] really wants to make this happen, but I’m not sure, you know, if we have enough people that would be a good fit for it.</i>’ But ultimately, she was willing to try it. Um. So, definitely having [the name of the community champion] on board, that was very important and then also the executive director ultimately, and then the social worker. (OTHC facilitator)</p> <p>“Um, I love cognitive programs and stimulating that activity and that social connection. So to me, um, I’m going to jump on board anything that contributes to that and that’s what I saw this as doing. Um, and even before we started, I didn’t have a real clear idea what kind of a project [the MBWC program manager] was talking about, but I thought, ‘Eh, it doesn’t really matter because if they’re working on a project, that’s a good thing.’ (Laughs.) So, um, yeah, I just, I just was on board from the time I saw it. (Senior living community champion)</p> <p>“Well I think as an organization and our leadership, our executive director being open, and being an open kind of community where it’s um– because I think sometimes when it’s unknown, we can feel threatened or, um, have lots of rules. So, I didn’t perceive that at all. I felt like there was, uh, from our executive director to [the name of the senior living community champion], the memory fitness coordinator, Life Enrichment, that everybody saw this as a potential opportunity and wanted to be open to that and bring that to the residents and then the residents being willing to take a risk and join something that was somewhat undefined but you know, come and explore this. Um, and so maybe that’s one of the best contributions or the most positive as far as an institution.” (Senior living social worker)</p>	This theme is about the senior living human resources.
A receptive community culture	<p>“The fact that she [(the social worker)] was already focusing on memory loss for those three months [(when OTHC occurred)], um, and was open to the idea of residents being involved in her presentations and things like that.” (OTHC facilitator)</p> <p>“I, um, commend [the name of the owner of the senior living community] is the owners, and the organization over the years is I think that there is very much a value of how do we continue to grow and provide the best services possible for aging in place or aging in, uh, you know, independence, autonomy, stability, those kinds of things.” (Senior living social worker)</p>	This theme is about factors that contribute to a community culture that is receptive to memory-loss programs, including senior living community

	<p>“Coincidentally we were already kind of moving into, um, a 3-month kind of series that we were going to be doing in the community on memory loss anyways, um, and so this fell kind of right into place. And so we were already having and our social worker was doing a presentation on memory loss, um, our nurse is doing a presentation and we’re having a nutritionist talk about—. So we already kind of through this course of these 3 months had kind of plugged in some, some other topics related to it and so this was a nice kind of addition. So I think that’s one thing that really helped it be successful is we were already having this bigger conversation about memory loss and so by the time the project ended and they had the, um, the suggestions and the output of the project, that just kind of added more momentum behind another conversation that we were already having. Um, I think that really, really helped ‘cause it just added another layer, another talking point, another, um, another opportunity, uh, to ask questions.” (Senior living executive director)</p> <p>“And I do think that when the residents did their presentation in front of all the other residents that started additional conversation and, and I think, sometimes when we do things in our communities we just, it’s kind of one, one conversation or one presentation and then we move on to the next thing. And so, something with like memory loss, um, I feel like it can take people awhile to feel comfortable talking or have the right opportunity or maybe not this time, maybe tomorrow I’ll say something. And so, um, knowing that that conversation had, there was a lot of those conversations that would be happening for the next few months, um, it really started to build some momentum and it was just another perspective of sort of the resident to resident perspective where we already, we’re having the nurse perspective and the social worker perspective and the nu-, nutritionist perspective, um, and so it was another, you know, another avenue to continue that conversation.” (Executive director)</p> <p>“If we did it again, I think if I could go back and I would have done more to publicize kind of throughout the project or maybe going into the project, um, to the other residents, what this group was doing instead of sort of waiting to the end. I think selling it kind of throughout like they’re hard at work and we’ll, we’ll see this final presentation when they’re done or giving more, um, recognition to those that were participating in the project kind of throughout it. Um, I think that would have done more to kind of buildup, uh, some anticipation, recognition, um, and kind of momentum behind it. They were kind of operating off to the side a little, I mean, I mean we did the initial request for participants and then there wasn’t really much we talked about with the rest of the residents until it was done. Um, and I think that’s something we could have done a little bit more of ‘<i>Hey, ask these people about this, this project they’re participating in,</i>’ or you know, to give a little bit more incentive, um, and correlation maybe between who’s in the project and what they’re doing, and why and—.” (Senior living executive director)</p>	<p>owners’ value or philosophy of operating the senior living community, concurrent community events, and on-going publicity of OTHC within the senior living community.</p>
Strategies that promote program	<p>“I think it really helped to have coffee for them too, that, that first time. That was kind of the icebreaker. Well, kind of drink our coffee and just socialize a bit and get to know [each other]. So, that’s just a good way to</p>	<p>This theme groups together codes that are relevant</p>

attendance	<p>start out.” (Senior living community champion)</p> <p>“Well, having a familiar face, though, I think is really important because, um, once they are aware that they have some cognitive issues going into an unknown, if they’re doing it on their own, can sometimes be very intimidating. Having somebody there that already knows them kind of bridges that gap. (Senior living community champion)</p> <p>“Then, the other thing I did was I reminded the residents every single week because, yes, they do have cognitive issues so I, I made sure that they either got a phone call the evening before or a flyer on their door to remind them.” (Senior living community champion)</p> <p>“And another difference would be it was a lot easier for me as far as not having to do reminder calls.” (OTHC facilitator)</p>	to providing a structure that encourages participants to attend the program, including weekly reminders, a familiar face, and refreshments.
Participants living on-site	<p>“People had a hard time finding the location last time, so, just doing it in a place where people are already living and there were staff that could literally take people from their room down to the, down to the program room. That was very convenient.” (OTHC facilitator)</p> <p>“Evaluator: How does it feel to meet 2 hours at a time every week, ‘cause the meeting was 2 hours every week? How did you feel about the 2-hour timeframe? Participant G: It doesn’t impact us very much, because the meeting was here, and this is where we live.”</p>	This theme is about the benefit of offering the program at the same location where participants live.
Participants knowing and incorporating their staff and available resources in the community	<p>“I think the participants, all being residents there and knowing about, everything about their community. Like the fact that they knew the staff and they were comfortable talking with them and they knew the different, um, avenues to get the word out about their tips like they knew about the newsletter and elevator flyers or whatever else they knew about all those things. So, I guess that’s kind of a, kind of an organization factor just that the residents themselves were familiar with the, um, the space.” (OTHC facilitator)</p> <p>“... the group was networking with the staff [(to carry out their OTHC DFCs project)], that was a very positive—, and very important because, um, they might have had a positive experience in the group on their own. But if they hadn’t had that support and validation from staff, I think it would have maybe been less satisfying for them.” (Senior living social worker)</p> <p>“Well, part of it is I’m the resident goof-off, and they know if I’m doing a group it’s going to be fun.” (Senior living community champion)</p>	This theme is about participants’ awareness and usage of what is available in their community.
Adequate planning before program implementation	<p>“I think [the name of the MBWC program manager] had reached out to [the name of the senior living community champion], and I kind of inserted myself a little bit to kind of say, ‘<i>Let’s think this through, let’s make sure what’s the timing going to be, what’s, you know, how many participants, how we’re going to get the participants</i>’ and so um, I think that’s really important to do that, that it’s not rushed too much in the beginning or kind of thrown together ‘cause I feel like you’ll have better success when you really can collaborate and really, um, make sure it starts out on the right foot” (Senior living executive director)</p> <p>“And so I think, I think you seem to have people from each kind of discipline or each department or different level in the community kind of reviewing the project a little bit, um, so everyone has the opportunity to kind of put their opinion in or their suggestions of ‘<i>How-, what can we</i></p>	This theme mostly represents the perspective of the senior living executive director, regarding the importance of program planning.

	<p><i>get more successful?</i> I think in general, you know we tend to do that in the communities anyways that there's nothing that really is organized or, or established in, in, in a silo, it really kind of takes a few different people looking at the idea to, to hopefully make it the most successful.” (Senior living executive director)</p> <p>“And our Life Enrichment Team, I mean they're normally planning the calendars a month or two out so you know in order for that to happen, it, it, the high—. (Pause.) I mean you can definitely start moving things around and um, and trying to make it work, but, you know if you're at that 3-month mark kind of planning out, I feel like that gives you, um, an appropriate amount of time to find a space, find a location, find the participants, get it organized so that's, you know, it's smoother” (Senior living executive director)</p>	
(Staff knowledge of) participant characteristics	<p>“And so I believe when we were approached, it was whether or not we could have our memory fitness program participate, instead, um, but you know after kind of reviewing what was being asked at the project and, or the participants, um, you know sort of my suggestion that maybe we branch out to the greater, the greater community.... I know if we had just, you know if, if [the senior living community champion] had just gone up the request to do it for memory fitness, it would have been a totally different, um, project, just, just those residents would not have been able to do what the ones had did participate and did.” (executive director)</p> <p>“It just sounds like the character of individuals that live at [the name of the senior living community] from what I heard compared to the other, um, communities owned by the same organization that they're, like really friendly and kind of down to earth people to begin with. So, maybe a little bit more eager to do things that would help them connect with each other for being inclusive.” (OTHC facilitator)</p> <p>“... having someone like, like [the name of a participant] who was very outspoken and I mean every day, she talked and had a lot to contribute, I think having someone like that is a big strength. If you have a group full of people that aren't really communicators or don't really want to talk about their experiences, um, then I think you could find some challenges for sure, um, going forward.” (OTHC volunteer)</p>	This theme is about participants' characteristics from the perspectives of senior living staff and OTHC staff.

Note. a. These themes include experienced or anticipated senior living-based facilitators from the perspective of interviewees.

## APPENDIX J: SENIOR LIVING-BASED BARRIERS: THEMES AND SUPPORTING QUOTES

Senior living-based barrier themes <sup>a</sup>	Supporting Quotes	Notes
Residents' negative preconception of memory loss and relevant programs	<p>“The only thing I could think would, that would interfere is if someone [a potential participant] didn't have a positive outlook from the beginning and, and really wasn't on board with it.” (Senior living community champion)</p> <p>“I think the other barrier is, and we touched on it a little bit, um, that didn't seem to rear its head too much here is sometimes making it, mmm, safe or, um, having it where residents are willing to take that risk and say I'm having some issues with memory. And I think that it's still an ongoing even as we provide services with memory fitness and brain teasing or, um, brain fitness is sometimes – maybe people don't want to come because they don't want to be like that, and so also making that meaningful that we can be wherever we're at. We can be at a more beginning stages of some memory loss, uh, or we can be at a further advanced and so sometimes I think the nature of memory loss is a barrier in itself, and so I was very impressed that there was this group that seemed to be willing to take that risk and come together and still come in there, but um – so I think the stigma, and we talked about that a little bit in the first talk, just the stigma around, uh, health issues and – anything that is mental health-ish, like memory, depression, anxiety. Um, so those are a couple of things I think of as barriers.” (Senior living social worker)</p> <p>“I expected, um, more barriers around people not wanting to self-identify as having memory loss within a retirement community. I thought there would be a lot of stigma against that and that nobody would want to be seen showing up to a class that had to do with memory loss.” (OTHC facilitator)</p> <p>“Okay. So I think that what they were talking about before um, how people are very um private about their memory loss, um, and they don't want to speak about it. Um, so if you have this group of people that are sort of driving the, you know driving this ah, movement of, of, of becoming more aware of memory loss and there are people in the community that don't want that, don't want to admit that they have a memory, you know memory issues and stuff. I think that you can create some animosity towards um, the community members that are in the program and the community members that are not.” (OTHC volunteer)</p> <p>“I think the barriers could be the residents, you know and their ability to participate in the program and follow along.” (Senior living executive director)</p>	This theme is about residents' negative perception of memory loss (e.g self-stigma) and memory loss-related programing.
Residents' (in)ability to participate	<p>“I think the barriers could be the residents, you know and their ability to participate in the program and follow along.” (executive director)</p> <p>“I didn't notice any negative effects. The only negative I might say is the two participants who had to quit because of physical issues were actually very disappointed to quit. They didn't really want to, but they</p>	This theme is about residents' ability or inability to participate the program, which may be affected

	felt like they had to.” (Senior living community champion)	by their cognitive or physical health status.
A lack of staff understanding about the program or close-minded leaders	<p>“And then, maybe just that initial barrier of, um, trying to explain, what is the program to the staff and having the staff feel like, “Yeah, we want to do it.” Like, that initial yes or no about are we going to host it or not, I think there’s—, there can be a barrier as far as understanding. ‘<i>Why are we doing this? Is there a benefit? What’s the benefit? Um. What is this even about? Yeah. Do we have space? Do we have time?</i>’ Yeah.” (OTHC facilitator)</p> <p>“I think our staff was educated on the program and so they were able to advertise and talk about it and ask questions and be prepared for the, the, your group that was coming through. So I mean potentially that could be a barrier if, if it wasn’t communicated in advance and people were kind of wondering who you were, what you we’re doing and why you were here and not giving it enough, um, importance.” (Executive director)</p> <p>“Um, barriers, um, well certainly I think, um, what we started talking with the last question about if, um, leaders are closed and, um, are kind of in the box, we’ve done it this way forever and this is the way we’re going to do it, that’s probably one of the biggest barriers.” (Senior living social worker)</p>	This theme is about senior living community staff attitudes and understanding of the program.
Competing with other programs for time and space	<p>“I mean the space [chuckles], I think, um, at least for us it’s really hard to find a room, um, in the time of day, in the time of week that worked for the students and the presenters and then also for our residents and not conflicting with other things going on and so I think that planning piece is really important that we could find a room that was available every, um, week that would be consistent, that, that wouldn’t be interrupted, um, and a time of day that didn’t conflict with other things going on in the community, that was one fear we had was, you know we would get ten people signed up but then as soon as the exercise class or the grocery shuttle is happening at the same time that people would bail and, and go do that.” (Senior living executive director)</p> <p>“Umm, if we had had a location where they didn’t—where that was a little bit more central of the building where they didn’t have to go all the way down. Unfortunately, our building doesn’t have quite as many meeting rooms as some other seniors’ retirement centers do, so in planning, um, that’s one thing I would encourage them to do is try to give you a room that is very centrally located.... Using the room that we used down there [for OTHC], I have a couple residents who won’t go down there if our group is going to meet there, just because it’s a bit of a walk” (Senior living community champion)</p> <p>“And the fact that they already have all kinds of activities going on, where, you know we’re initially there like, ‘<i>Well, we already have some, you know, exercise class on Wednesday morning, nobody’s going come to this other thing.</i>’ So, yeah.” (OTHC facilitator)</p>	This theme is about competing with existing programs in the senior living for time and space.
Inadequate advertisement	<p>“I think a barrier could be, um, if we, if you don’t do enough sort of advertising and marketing for the program, um, you know, we talked, we talked about it at some resident meetings ahead of time the project was coming and sort of verbally communicating what it was and what we’re looking for, ‘cause sometimes it just passing out the flyer, you know (Chuckles), it’s not enough.” (executive director)</p>	This theme is about marketing the program and communicating what the program is about to potential

	<p>“And I think that’s why some people kind of dropped out because they didn’t really know what they were doing there, maybe that had something to do with their condition but it, but I think it had a lot to do with the, the lack of communication on, on the program’s part of, of really accurately communicating what the purpose was.” (OTHC volunteer)</p>	<p>participants.</p>
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Note. a. These themes include experienced or anticipated senior living-based barriers from the perspective of interviewees.

## APPENDIX K: ADDITIONAL BENEFITS: THEMES AND SUPPORTING QUOTES

Themes	Supporting Quotes	Notes
An opportunity to help, stay engaged, and be autonomous	<p>“Yeah, and I think they enjoy thinking, or you know not just thinking but do, feeling like they’ve contributed or helped a student, you know or help someone that’s working on something that they can be a part of that or influence that um, as well as, as a sort of a sub-, a byproduct of the, the rest.” (Senior living executive director)</p> <p>“The other thing – I’d have to think about this but I think a good majority of the group, maybe 2/3 or what we would call independent living so they’re not necessarily receiving assisted living services and sometimes I think they can be independent living a little more isolated because they’re not necessarily engaging – they might be coming to a program but they’re not necessarily having a conversation about their concerns, um, or – um, and so I think that they also then, probably the benefits for them...” (Senior living social worker)</p> <p>“I think it's the autonomy, I think it's staying engaged and involved to something, I think it's advocating and engaging and having empathy for the neighbors, uh, you know taking ownership of the culture of the community, um, and the-, and getting that movement kind of behind that.” (Senior living executive director)</p>	
Destigmatizing and awareness raising	<p>“I think it starts the process of them, um, identifying and maybe forgiving themselves a little bit and not feeling so resistant or embarrassed if they can see that they’re doing well by others, um, and I think that was one of the biggest surprises of the project was, um, it, it-, and not knowing much about how the, how it was going to play out was really, you know, the focus being on what that group was going to do for the other residents and really seeing that the ones that participated in the group probably benefited the most, you know, so far, um, because they have all of these great tips and suggestions and, um, the outcome of their project, um, which will have impact, uh, kind of maybe one or two steps removed for the rest of residents in the community but those, you know eight or so that participated in the project had a far, uh, I think a far bigger, uh, shift, uh, and how they view others.” (executive director)</p> <p>“I think it really helped them see a different perspective of their neighbors, um, and I know sometimes, um, residents can get frustrated with, uh, or may not completely understand what their neighbors are going through or if it's a friend that they've been dining with for months or years and then that person starts to, uh, show some decline or change. Um, it's not as easy for them to recognize as you would or as I would think, you know this is their peer group, this is their world and, um, identifying with someone who's experiencing memory loss I feel like that doesn't sometimes come to the surface as quickly as, as you may think. Um, so I think it was a great kind of start to a shift and, and advocating and noticing and identifying and um, having some empathy.” (executive director)</p> <p>“– I think the ability to come together and see they’re not alone and to talk about memory loss, to maybe delve into it. It seemed like it wasn’t</p>	This theme is about removing or reducing self-stigma of memory loss and increasing awareness of memory loss in the senior living community (both residents and staff).

	<p>so much superficial like ‘<i>Oh, here’s a puzzle. Do this puzzle.</i>’ But more of an opportunity to take a life puzzle and say, ‘<i>How do we – what do we want to do and what kind of impact if any do we want to have and then how do we go about that.</i>’ So I think it really engaged them in problem solving, which is always good for memory. Um. It also – as I said earlier, I didn’t use the word, but I think it removed some of the shame and some of the barriers to, um, to feeling a part of a community and maybe to, um, at, at times feeling vey self-conscious so, again, you don’t engage.” (Senior living social worker)</p> <p>“I was kind of amazed at how a couple of them were able to go from maybe feeling a little insecure about being identified to actually sharing their story and talking” (Senior living social worker)</p> <p>“Even the staff were appreciative of the comments and are getting on board, so that’s really cool. Yeah. Which is really—I mean, the, obviously, the nursing staff already have a lot of contact with those but the housekeeping staff and maintenance and even the servers in the dining room were going, ‘<i>This is pretty cool. Can we have one of those?</i>’ I said, ‘<i>Just stay tuned. I’ll get you some printed.</i>’”</p>	
Community-building and lasting impact	<p>“I felt like – so not only did it help them on an individual but I felt like it brought together like what – how do I want to be treated and then how do I go back communicating that, and how do we make this a part of an ongoing communication in our community.” (Senior living social worker)</p> <p>“I don’t know if that group will stay intact so much or if it will become – I would love to see it become an ongoing kind of working group, you know, so I don’t know what the future holds.” (Senior living social worker)</p> <p>“I would almost feel like having the program in a retirement community, where everyone does live together, you’re bringing people together that don’t necessarily know each other until after the group you know is complete, concluded. So I feel like making those connections and those friendships might help to solidify a long term memory of the program itself by seeing maybe you know some like [a participant’s name] seeing [a participant’s name], who they wouldn’t have maybe interacted before but they have that in common now so they’re like, maybe like, ‘<i>Why do I know that? Oh yeah we did the Our Time Has Come thing.</i>’ (Chuckles.) You know? So, um, yeah. So I think, I think having it, I personally think having it in one place with a group of people that are all kind of know each other is beneficial in that way.” (OTHC volunteer)</p> <p>“And so it was a good, uh, outlet for them to feel like they were advocating for others and, and, and creating of a culture or a shift, um, which I think will last, um, especially if we can keep some of the pieces going, um, because a lot of times in a community setting, um, you know, you either have people kind of rallying together and moving in the same direction or it seems like people maybe are more in resistant to each other or not wanting to identify, you know and so therefore kind of ostracizing people, and so I think it really, it, it, I think it really showed that there’s a lot more we can do in the community in general to really get residents advocating and working, um, for each other instead of against each other though that doesn’t</p>	This theme is about how OTHC brought the participants together, reinforced a resident culture of advocacy and self-advocacy, and the continuation of making the senior living community more memory-friendly after the program.

	<p>always have to be the staff sort of paving that way that I think the more you can get the residents kind of initiating the movement, um, the more buy-in you have and as well as, um, maybe more successful.” (Senior living executive director)</p> <p>“We’re working on establishing a volunteer program right now and so that kind of was a good momentum building into, um, seeing how much the, the participants got out of the program and, and then using that to encourage further participation in similar type, giving type, um, advocacy opportunities (Senior living executive director)</p> <p>“Um, they are already talking about wanting to work together as a group on another project and that just really excited me. So, we’re in the process now of trying to find another volunteer project that they can do, either for the building here or in the community, um, and encouraging them to look into ways to start groups and to provide groups for them. So, I, I, I think community is so important to keeping a good quality of life and a sharp brain, so any time we can encourage that community—and it really did that. The group bonded really well.” (community champion)</p>	
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