

Implementation and Impact of the Dementia Friends Pilot in Washington State

Alisa Tirado Strayer

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Committee:

Miruna Petrescu-Prahova

Basia Belza

Clara Berridge

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Alisa Tirado Strayer

University of Washington

Abstract

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Alisa Tirado Strayer

Chair of the Supervisory Committee:

Miruna Petrescu-Prahova, PhD, MA

Department of Health Services

While the number of people with dementia is growing, there are currently limited opportunities to have conversations about dementia and the stigma that surrounds it. To begin to disrupt that stigma, we need to create spaces to learn about dementia and learn how to support those facing dementia. Dementia Friends, a global dementia awareness program, was developed to address this need. The program recruits and trains Dementia Champions who then host and recruit community members to participate in 90-minute dementia-awareness sessions. The purpose of this study was to evaluate the implementation and impact of the Dementia Friends program piloted in Washington State. We explored how the session impacted Dementia Friends participants' attitudes towards people with dementia, what facilitated and hindered the implementation of the program, and what needed restructuring.

We recruited 15 Dementia Champions, who in turn recruited 214 Dementia Friends participants. The Dementia Friends participants were given three surveys: an immediate pre-session survey, an immediate post-session survey, and a 1-month post-session survey, each including the Dementia Attitudes Scale (DAS) and open-ended questions to assess Dementia Friends participants' attitudes towards people with dementia. The Dementia Champions

participated in 30-minute interviews once they had hosted all of their Dementia Friends sessions to discuss the facilitators and barriers to being a Dementia Champion.

We found that there was a statistically significant improvement in attitudes towards people with dementia, maintained through the 1-month follow-up. Dementia Friends participants also discussed appreciating the group atmosphere and accessible information, which helped them see the importance of understanding and patience when communicating with people with dementia. In terms of implementation, the Dementia Champions discussed the importance of individual Champion characteristics (such as strong social networks or experience giving presentations), organizational support, and accessibility of Dementia Friends sessions. Both Dementia Friends participants and Dementia Champions suggested several program alterations, such as including more clinical information, allowing more time for interactions between Dementia Friends participants, recruiting Dementia Champions from diverse backgrounds, increasing logistical support to Dementia Champions, and better equipping Dementia Champions to organize and host their sessions.

Both Dementia Friends participants and Dementia Champions agreed that the Dementia Friends program is creating an important space to hold conversations and increase awareness about dementia. While improvements were suggested to better support Dementia Champions and improve accessibility of the program, the Dementia Friends program should be considered as a tool to continue spreading dementia awareness.

## 1. INTRODUCTION

Dementia is a growing concern across the globe, with an estimated 50 million people worldwide living with dementia (WHO, 2019). In the U.S. alone, there are more than 5 million people living with Alzheimer's disease, the most common form of dementia (Alzheimer's Association, 2020). While a significant and increasing number of people live with dementia, care for someone with dementia, or know someone with dementia, there are limited opportunities for conversations about dementia and the stigma that surrounds it. To begin to disrupt the isolation that occurs before and following a dementia diagnosis, we need to create spaces to learn about dementia and learn how to support one-another by facing dementia directly.

Dementia Friends (DF) is a dementia awareness program developed in the UK. The format of DF follows a train-the-trainer model. The coordinator of the regional branch of the program is called the Master Champion, who recruits, trains, and supports the volunteer trainers, called Dementia Champions. The Dementia Champions are recruited and trained to host and deliver 90-minute Dementia Friends (DF) session presentations to their social networks. Dementia Champions have significant autonomy in this role, choosing when to host their DF session, where to host it, and who to invite. These DF sessions cover five key messages about dementia, provide dementia-specific communication tips, and invite attendees to commit to an action that will improve the lives of people with dementia in their community.

Previous research has shown that DF is effective in increasing DF participants' awareness and attitudes towards people with dementia (Cowen, 2019; Gibson et. al., 2018; Michell et. al., 2017; Davison et. al., 2019). Dementia Champions report that it is a meaningful experience to present DF sessions, due to learning new skills, developing new relationships, and feeling like they are making a difference in the lives of people with dementia (Bale & Jenkins, 2018). While

these studies have started an essential conversation about the effectiveness of the DF program, there are several gaps across the literature. These studies have primarily recruited nursing students for Dementia Champions and DF participants. Expanding the perspective to community members outside of the nursing field would give a deeper perspective on how the program normally runs. There has also not been a study that assesses both the DF participant and the Dementia Champion experience. Additionally, no study has examined the ways that the DF program has been implemented. These areas need to be examined before further dissemination given the unique structure of the DF program.

The purpose of this study was to: 1) describe the impact of DF sessions on participants and Dementia Champions'; and 2) evaluate the facilitators and barriers to implementation of Dementia Friends in three counties in Washington State. Our results have the potential to inform further dissemination and implementation of DF in Washington and beyond.

## **2. METHODS**

Our study used a mixed-method design to answer our research questions. The study took place in three counties in Washington State. Our team included the Master Champion, who is the administrator for the program and trainer of the Dementia Champions; 15 Dementia Champions, who presented the 90-minute DF sessions; and DF participants, who attended the DF sessions. We collected data on DF participants from surveys distributed before and after the DF session. We also collected data on Dementia Champions from surveys distributed before and after they presented their sessions, as well as 30-minute semi-structured interviews after they presented all of their sessions. Our study was funded through local organizations and city government agencies. The University of Washington Institutional Review Board approved the study and determined that it did not meet the regulatory definition of human subjects research.

## **2.1 Participants and Procedures**

The study took place in Yakima, King, and Jefferson Counties in Washington State from September 2018 to September 2019. Our goal was to enroll 15 participants to train as Dementia Champions. We conducted recruitment through word of mouth, outreach to community organizations, and distribution of flyers at conferences and community events. Participants interested in becoming Dementia Champions had to attend a 3-hour in-person training given by the Master Champion and commit to deliver DF sessions to at least 20 people through one or multiple DF sessions, with the intention of reaching at least 150 DF participants across all Dementia Champions. Dementia Champions attended their training in either January or February 2019 and then had four months to organize their DF sessions. Dementia Champions were asked to schedule sessions, recruit participants, and secure venues for their sessions, with support available from the Master Champion as needed. Each Dementia Champion received all necessary printed materials (except flyers to advertise their session), an optional PowerPoint presentation to accompany their session, several pamphlets about upcoming community programs on dementia to distribute, and a \$60 grocery store gift card to purchase refreshments for their session. After Dementia Champions delivered their sessions they received a \$25 gift card for their participation in the pilot.

## **2.2 Data Collection**

We developed and administered five surveys: a pre- and post-training survey for the Dementia Champions; and a pre-session survey, an immediate post-session survey, and a 1-month post-session survey for DF participants (surveys are provided in the Appendix). Each survey included the Dementia Attitudes Scale (DAS), which measures knowledge about dementia and comfort around people with dementia (O'Connor & McFadden, 2010; Cowen,

2019; Kimzey et. al., 2016; George et. al., 2014). The DAS is a 20-item instrument using a 7-point Likert scale from 1 (strongly disagree) to 7 (strongly agree). A higher score indicates a more positive attitude towards someone with dementia.

Surveys also included non-identifiable demographic items such as race, gender, age and prior experience with persons with dementia. The two DF participant post-session surveys also included 9 open-ended questions such as “what was meaningful to you about this [DF session] experience?”

Dementia Champions were also invited to participate in a 30-minute semi-structured interview over the phone conducted by the first author. Dementia Champions were asked about their reflections and suggestions on the implementation of the DF pilot.

## **2.4 Analysis**

We analyzed changes in DAS scores using paired t-tests in R (2019). This analysis evaluated the mean change in DF participant DAS scores between the pre-session survey and immediate post-session survey, as well as between the pre-session survey and 1-month post-session survey. We analyzed the total DAS score while also analyzing the knowledge score and the comfort score separately. Linear models were used to assess the relationship between demographic characteristics and mean DAS scores.

We analyzed the post-session open-ended survey data through thematic analysis. The first author coded the responses to find emergent themes. One of the co-authors (M.P.P.), an experienced qualitative researcher, consulted on the themes and suggested alternative ways to aggregate codes into themes. Additionally, we analyzed the responses to the question “What action do you commit to taking after listening to this session?” We reported the number of participants who chose a given action and how many reported completing that action.

Dementia Champion interviews were audio recorded and transcribed verbatim. Two coders analyzed the transcripts using thematic analysis (Braun & Clarke, 2006). The first author generated an a priori codebook based on initial readings of the interviews. From that initial codebook, both coders independently coded the same three interviews. The coders then met to discuss discrepancies in coding results, revise the codebook, and reach consensus for all codes. The first author then coded the remaining interviews based on the updated codebook.

### **3. RESULTS**

We recruited 15 Dementia Champions, nine in King County, five in Yakima County, and one in Jefferson County. As depicted in Table 1, the Dementia Champions were predominately women (87%), the average age was 53 years (range: 26 - 78), and 8 (53%) identified as white. Eleven (73%) Champions worked full or part-time. All Dementia Champions had a close relationship with someone with dementia and all DF sessions were held in English. Two Dementia Champions dropped out after attending the training, but were replaced by the first author and a colleague with DF training to ensure the pilot would reach the target number of total DF participants.

[Table 1 about here]

The 15 Dementia Champions organized a total of 22 sessions, each averaging 10 participants. Three of these Dementia Champions were not able to organize a session. Sessions were held in Dementia Champions' homes, local community centers, classrooms, and assisted living facilities. In total, 214 DF participants completed the pre-session survey, 210 completed the post-session survey, and 101 completed the 1-month post-session survey. DF participants at baseline (n = 214) were predominately women (71%), 162 (81%) identified as white, and the average age was 56 years (range = 19 - 93). Fifty percent of DF participants lived in a rural area.

Prior to attending the DF session, 70% of participants had never received formal education about dementia, but 59% felt at least somewhat knowledgeable about dementia. Additionally, 21% had no prior connection to persons with dementia.

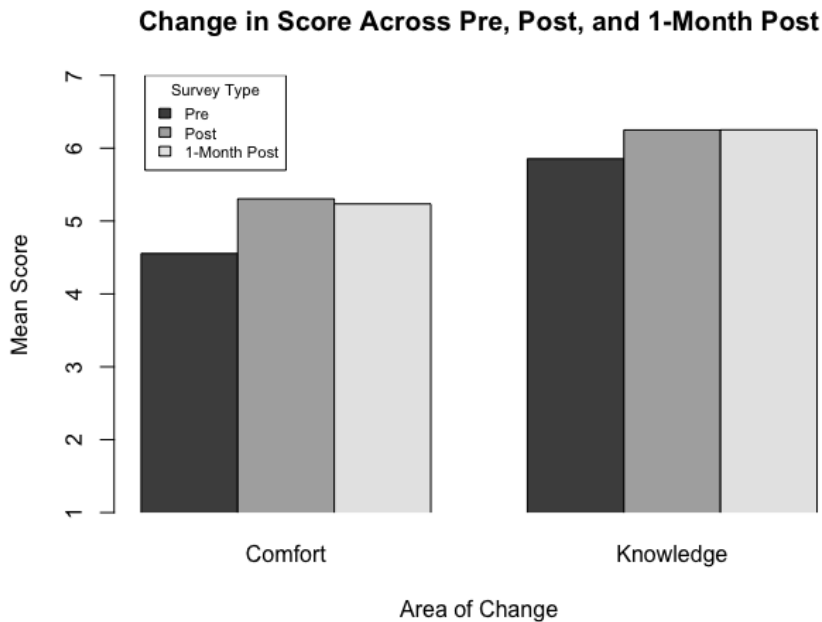
For the 30-minute interviews, 12 of the 15 Dementia Champions participated, giving feedback on their experience being in the DF pilot. As the first author was one of the Dementia Champions, they did not complete the interview or any evaluation materials. One Champion did not respond to attempts to contact and another Champion agreed to an interview, but was ultimately unable to due to family obligations.

### **3.1 Impact**

#### **3.1.1 Impact of DF Sessions on Participant Attitudes**

To assess the impact DF sessions had on participant attitudes towards people with dementia, we analyzed the change in scores for the pre-, post-, and 1-month post-session DAS items. Across the overall DAS, there was a significant difference between mean scores of overall attitudes from pre- to post- survey ( $p < 0.001$ ). This difference remained from pre-session survey to the 1-month post-session survey ( $p < 0.001$ ). To better understand these results, we divided the analysis of DAS questions into two sub-categories suggested by the scale developers: comfort with persons with dementia and knowledge about dementia.

*Figure 1: DF Participant Change in Score from Pre-Session Survey (n=214) to Post-Session Survey (n=210), and 1-month Post-Session Survey (n=101)*



### 3.1.1.a Comfort with Persons with Dementia

Participants reported an increase in comfort with persons with dementia from before attending the DF session (M = 4.6, SD = 1.1) to after attending the DF session (M = 5.3, SD = 0.8) ( $p < 0.001$ ). This trend persisted from before the session to 1-month after the session (M = 5.2, SD = 1) ( $p < 0.001$ ). We also tested differences in the impact of DF sessions on DF participant outcomes by demographics. This showed a slightly smaller change in comfort for Black DF participants from pre-session survey to post-session survey compared to the other DF participants ( $p < 0.02$ ). There was also a statistically significant difference in the impact of DF sessions on comfort based on which Dementia Champion delivered the DF session ( $p < 0.05$ ).

### 3.1.1.b Knowledge about Dementia

As with comfort, there was an increase in knowledge from before the session (M = 5.9, SD = 0.8) to after the session scores (M = 6.2, SD = 0.7) ( $p < 0.001$ ). This trend persisted for the 1-month post-session results (M = 6.3, SD = 0.7) ( $p < 0.001$ ). We also tested differences in the impact of DF sessions on participant outcomes by demographic characteristics and found a

slightly larger change (increase?) in knowledge for Hispanic or Latino DF participants from pre-session survey to post-session survey compared to the other DF participants ( $p < 0.02$ ). There was also a statistically significant difference in the impact of DF sessions on comfort based on which Dementia Champion delivered the DF session ( $p < 0.05$ ).

### **3.1.2 Strengths and Weaknesses of the DF Session**

In the post-session survey, DF participants responded to questions regarding what was most valuable about the DF session, what were the strengths and weaknesses, and how to redesign the DF sessions. DF participants found the most valuable aspect was learning how to better communicate with persons with dementia (33%). They stated the greatest strength of the DF session was the clarity and quality of content (33%). Forty-two percent of DF participants believed the information was too general. Forty-six percent thought nothing should change in the DF session. For each of the themes, we display the full findings, including the number of participants who provided an answer and an example quote, in Table 2.

[Table 2 about here]

In the 1-month post-session survey, DF participants responded to additional open-ended questions about the lasting impacts of the DF session. DF participants stated the most meaningful aspect of the DF session was gaining knowledge about dementia. All DF participants stated the DF session was worthwhile to expand, with 40% stating it was important because the DF session expanded knowledge about and compassion for people with dementia. Forty-four percent stated they would recommend adding more specific information about dementia if the program was redesigned. For each of the themes, we display the full findings, including the number of participants who provided an answer and an example quote, in Table 3.

[Table 3 about here]

DF participants were asked in both the post- and 1-month post-session survey what action they will take given the information they learned in the DF session. This question is asked across all DF sessions internationally. DF participants are given ten options, ranging from calling a legislator about the needs of people with dementia to practicing patience when talking to someone with dementia. Table 4 shows the percent of responses for each option. In the post-session survey (n=180), the five most common responses focused on impacting individuals and were smaller in scope, including carrying out a personal action and encouraging friends to attend a DF session. Each DF participant on average selected three actions. In the 1-month post-session survey (n=101) the same five actions were most common, but fewer DF participants selected multiple actions and fewer selected community advocacy level actions.

[Table 4 about here]

### **3.1.3 Dementia Champion Perceptions of Impact**

Dementia Champions felt that the DF program was effective in changing attitudes towards people with dementia, due to it being different from other programs, challenging stigma, and building community within the session. They appreciated that DF took a different approach by bringing a wider range of people to the program than other dementia education programs, not just those personally effected by dementia. Additionally, Dementia Champions stated that DF participants appeared to appreciate that the DF session was part of a state-wide initiative. For example, one participant said, “I found that people, when they felt like they were contributing towards to a greater cause, like yay, I’m learning a little bit more about dementia, but well, I might be helping Washington State become more impactful overall, and helping people who are living with dementia.” According to Dementia Champions, the range of people the DF session

attracted and the broad social impact it had appeared to deepen the engagement of DF participants.

Champions also reported that DF sessions seemed to challenge stigma that DF participants might have unknowingly held. One Champion recalled that “...I watched people's faces, and I have people say, My God, I never knew this.” They also saw DF participants gain confidence in their interactions with persons with dementia. This confidence appeared to impact DF participants’ intention to respond differently to persons with dementia, as illustrated by this statement:

Everybody who attended had a new face on dementia. I had one banker says, ‘I didn't realize what dementia looked like.’ I had an insurance lady saying ‘I'm going to be just a little bit more patient to those who come in. When they're not paying the bill, maybe you know, give them a call, say hey, you know, maybe I can come and help you.’

Another Champion described an unexpected phenomenon that others also noted, explaining that “And then people were talking, and they didn't get up and leave [at the end of the session], they stayed and chatted and then grabbed some food and just talked and talked.” Beyond gaining awareness about dementia, Dementia Champions observed community building between participants.

### **3.2 Implementation**

In this section, we present several themes related to DF implementation that we identified in the interviews with Dementia Champions as well as in the open-ended section of the DF participant surveys: Champions’ motivation for participation in DF, the accessibility of DF sessions, facilitators and barriers to hosting a session, and structural changes needed to have a

successful program. In this section, many of these suggestions were brief and to the point; we include more detailed and relevant quotes where available.

### **3.2.1 Champions' Motivation for Participation in DF**

Champions stated that they were initially motivated to be a Dementia Champion so they could learn more about dementia, engage in dementia advocacy, and do community building in their community. This desire to engage in their local community was captured by one Champion:

It sounded like a really cool opportunity to learn more about dementia as a whole and the things that I could do in my own day to day life as an advocate or an ally to those who have dementia or live with people with dementia. But also that opportunity to then be able to take that information out to the community was really interesting to me.

Several of the Champions were also past or current care-partners of persons living with dementia who wanted to be connected to a broader community spreading education about dementia. One of the Dementia Champions who was a current care-partner said, "In my case, once I placed [my husband], I enjoy staying involved in things." Having ways to continue advocating for their loved one helped maintain that bond, even when the Champion was not with their loved one with dementia.

Dementia Champions were motivated beyond dementia advocacy and finding community. They also saw the Dementia Friends program as a way to gain skills, such as community organizing and public speaking. As one Champion stated, they were interested in DF because of "the component of being able to practice some community organizing, and presentation giving or gathering and discussing a communal topic of interest." For some, DF

provided a supportive, structured, and friendly atmosphere to practice these skills outside of an academic or professional realm.

### **3.2.2 Accessibility of DF sessions**

In the post-session survey, participants were asked eight questions about the accessibility of the session and the Dementia Champion's ability to present the information. Results are summarized in Table 5. Overall, 83% of DF participants reported having an excellent experience in the session. Eighty-eight percent thought the information was easy to understand and 90% could clearly hear and see the Dementia Champion who was presenting. With regard to the Dementia Champions' ability to present the material, 77% of DF participants thought the Champion showed excellent expertise, 85% thought the Champion presented the material very clearly, and 91% thought the Champion was extremely responsive. Eighty-two percent of DF participants also thought the Champion showed excellent cultural appropriateness. Time management was a lower percentage, with 78% assessing that the Champion showed excellent time management.

[Table 5 about here]

### **3.2.3 Facilitators and Barriers to Hosting a DF session**

Through this process, Dementia Champions had different degrees of ability to organize and then host the session, facing challenges finding a venue or finding participants. Because it was apparent in the Dementia Champion interviews that there were different factors affecting Champions' ability to organize a session as well as host a productive one, in this section we distinguish between facilitators and barriers to organizing a session versus the facilitators and barriers to having a productive session.

#### **3.2.3.a Facilitators and Barriers for Organizing the Session**

Dementia Champions discussed several administrative aspects that facilitated their being able to organize a session such as check-ins by the Master Champion, having a clear vision for their session, having printed materials, a PowerPoint presentation, and a gift card for refreshments. They emphasized how the administrative supports were key because it gave them resources and guidelines to follow, taking some of the logistical pressure off of them.

They also discussed that having a strong social network helped them navigate organizing their session. They could reach out to friends and other community through word of mouth to get participants and could use their personal connections to find a venue. As one Dementia Champion stated:

I wasn't worried about any of it, because I'm connected already with my church and with the senior center. So I knew that if I wanted to do a presentation, I could go to either location and get a secure space without problem.

However, what Dementia Champions cited as what most helped them organize the session was having prior experience giving presentations like DF. They knew how to organize a session, who to contact, how to reach out to participants, and could do all of this quickly and without much anxiety.

While there were facilitators to organizing a session, Champions also experienced several barriers, such as scheduling, finding a venue, advertising to non-friends, and managing outreach from the Master Champion. Several of the Champions who were attracted to the DF program were already involved in many different organizations, giving presentations, and being community leaders. Adding another commitment to their schedule, despite their enthusiasm for the DF program, was challenging. Alternatively, Champions who did not have strong ties to organizations or communities struggled to organize a session due to feeling unsure of how to

contact a venue, what kind of venue to reach out to, or how to find participants outside of their friend group. One Dementia Champion who was not able to organize a session stated:

I think the biggest challenge for me was the advertising... my friends were more than willing but I think I wanted to have a little bit more far reaching of a grasp. It just made me very anxious to try to find spaces where I would think people were interested in that particular material [Dementia Friends].

Champions also discussed wanting to make sure the time and venue of their DF session was accessible to a diverse audience. Trying to accommodate a wide range of abilities, schedules, and neighborhoods in one session made it difficult to organize sessions. This was even more difficult when Champions struggled to make contact with a venue.

A final barrier that Champions discussed was discomfort with the check-in calls or emails the Master Champion provided every two weeks. Some of the Champions expressed feeling guilt when they were not making progress organizing their session and would avoid responding to the Master Champion or avoid organizing the session. As one Champion described, "I think there is that difference between what is enjoyable communication and what is useful communication. I didn't enjoy getting the check-in email sent out, but it was useful." While Champions felt the contact occasionally motivating them, they also did not like feeling micromanaged.

#### 3.2.3.b Facilitators and Barriers for Having a Productive Session

Once Dementia Champions were able to organize a session (schedule a venue and find participants), they still needed to host the session. Champions reported several aspects that facilitated a productive session: role-playing the session script at their training, having a personal connection to the material, flexibility of script, and the conversations between participants. The Dementia Champions reported that role-playing hosting at the Champion training helped them

prepare for their session since they had time to practice and get feedback from other Champions.

One Champion who had not given a presentation like this before said:

I think the role play was helpful...It seemed like everyone who was there came from very different walks of life, and [my partner helped me] think about how to approach the information and potential questions that people would have...I was able to then understand the material a little better.

This thread of sharing personal insights about dementia remained important within the session. Champions reported that DF participants responded positively when Champions and other participants shared their personal connection to the material. A Dementia Champion who gave a talk to a group of students said, "I had some people who worked in memory care, and they had all kinds of examples and made the whole thing very interesting. And I had some of my own examples, but not as many." Sharing those personal stories and insights, whether coming from Champions or from other participants helped illustrate the ideas in Dementia Friends and create a bond across the group. Many Champions mentioned that when there were these bonds between participants, their enthusiasm, curiosity, and questions made the session engaging and meaningful: "People were able to share things without feeling inhibited, and they laughed, and we made it fun."

There were also several barriers that inhibited Dementia Champions from having a productive session. Barriers that emerged on the day of the session centered around coordinating logistics, responding to questions, and lack of participant diversity. Champions struggled primarily with coordinating the logistics of hosting the session such as setting up the space, handing out and explaining surveys, and managing timing. Several Champions discussed struggling with the timing and juggling different pieces of the DF session; as one Champion

stated, “I wasn't quite sure how long each piece of the info session would take, and I felt rushed. I mean, I had a general sense - I had written in timing, but still it was a really large group.” This was true for both Dementia Champions with significant experience giving presentations and those with less experience.

Part of struggling with the timing also appeared to be connected to the challenge of holding multiple roles during the DF session, particularly if friends attended the session. One of the very experienced presenters said, “I think maybe because the sessions I did were more informal, it felt a little bit messier to navigate that. Like, I'm your friend, and I'm the hostess, and here's your stuff, and make sure you sign in.” Champions in both formal and informal settings stated struggling to manage the multiple responsibilities required during the DF session.

Another challenge arose when Champions struggled to respond to questions, due to DF participants wanting specific or clinical information or when participants shared challenging experiences surrounding dementia. One Dementia Champion, who worked on dementia, stated, “Something that I felt very aware of, during both of the sessions that I did, was not having the level of medical expertise to be able to answer people's questions.” Even for Champions who had formal education and personal experiences with dementia struggled with the specificity of questions and the feeling that they should have answers for all DF participant’s questions.

A final barrier that Dementia Champions reported was a lack of diversity in their sessions, in terms of age, race, or education, which they thought limited the conversation. Several Champions brought this up for sessions that lacked age diversity. Champions also discussed feeling that the voices of persons living with dementia were not included in the presentation. One younger Champion described this feeling: “I was aware of feeling

disconnected from older adults with dementia ...It was like, wow, here I am talking about dementia, and I had one older adult come to one session, otherwise it was all young people.”

### **3.2.4. Structural changes needed to have a successful program**

During the interviews, Dementia Champions also spoke about three structural changes to improve the DF program: enhanced Champion training and support, increasing advertising support, and altering the session structure.

#### 3.2.4.a Enhanced Champion Training and Support

With regard to the training itself, Dementia Champions identified opportunities to better support future Champions who have less experience recruiting participants and giving presentations. They specifically encouraged spending more time in the training practicing the script. They also suggested providing concrete tips for how to recruit participants and how to give a presentation, including outreach templates for email, phone calls, listservs, or social media posts. Additionally, they suggested providing a script for frequently asked questions for Champions when they are unsure of how to respond to more clinical or medical questions.

Champions also expressed appreciation for the diversity in the room during their training, which helped them learn the material from different perspectives and feel more comfortable. They each thought having diversity in the Champion training would be important to maintain in future training sessions.

To motivate Champions beyond check-in calls and emails from the Master Champion, Champions suggested adding optional community building opportunities for Champions where they can motivate and support one another to organize sessions. Having opportunities to meet with one-another and be reinvigorated in the work, particularly if there has been a long period of

time since the training, could allow them to brainstorm, commiserate, and get new ideas for future DF sessions.

Most of all, the Champions emphasized the need for individualized support based on a Champion's experience, network, and availability. Particularly for current care-partners, this volunteer position can be a substantial time commitment. Champions endorsed offering supports for care-partners who are interested in participating and have much to offer, but with limited availability.

#### 3.2.4.b Increased Support for Advertising and Outreach

Champions suggested that the Master Champion create relationships with local organizations who are open to being a venue to make it easier for Champions to find and contact venue spaces. This would also potentially facilitate easier outreach to participants who were active at that venue, such as a church or community center.

The Champions also learned that different advertising approaches were needed for different groups. One Champion held a session at a Senior Living Community and found that participants were more open to attending since she was a known resident there as well. Several other Champions advertised through colleges and they recommended reaching out to the administrators very early to reserve a space and advertise because it could take time for the request to be processed.

#### 3.2.4.c Alternative Session Structure

A last area of change was within the session structure. Champions wanted to make sure it was a welcoming environment for a range of people. To do that they had suggestions about both the locations where DF sessions are held and the content of sessions. Champions suggested making sure that DF sessions and Champion trainings were held in places open to a wide range

of access needs and reach neighborhoods that may not often have programs like Dementia Friends. Sessions would need to make sure there are accommodations, such as for hearing and mobility needs and chemical sensitivities.

Champions also stated that future Champions will have to be mindful of their audience's needs: if they need additional time to complete forms, get settled, or need a slower presentation. Champions should be given instruction on how to gauge when to slow down the information. There was also a recommendation to reserve a longer time to give the session so it does not feel as rushed, possibly reserving two hours instead of one and a half hours. Several Champions suggested removing the surveys that were part of the pilot as we move forward because participants voiced some confusion and difficulty completing them, such as unclear directions and small font, or needed extra time to complete.

Regarding the content in DF sessions, one Champion discussed the importance of using pronouns in introductions to create a welcoming environment for participants in the LGBTQIA+ community. Several other Champions thought it would be important to incorporate the voices of persons with dementia and care-partners, through a video or through having a person with dementia or a care-partner be a Dementia Champion. As one Champion stated, "One suggestion I would make would be to have some videos, some interview videos, maybe some stories about caregivers...maybe have a caregiver that has seen the presentation say what this presentation means to them."

### **3.3 Summary of Suggestions for Program Alterations**

Based on the feedback from Dementia Champions and DF participants, there were several key areas of alterations suggested regarding both DF content and implementation. Table 6 summarizes these suggestions.

[Table 6 about here]

## **4. DISCUSSION**

This study evaluated the impact of a DF program on participant attitudes towards people with dementia in three counties in Washington State. We also evaluated the implementation process for both the DF program overall, such as the recruitment and training of Dementia Champions, and the DF sessions. We found that DF sessions are effective at positively impacting people's attitudes towards dementia, but that the implementation of the program needs adjustments to provide the necessary supports to Dementia Champions.

### **4.1. Impact**

We found that DF sessions are effective in impacting DF participant attitudes towards persons with dementia, which aligns with previous research on DF sessions (Cowen, 2019; Gibson et. al., 2018; Michell et. al., 2017; Davison et. al., 2019). Both DF participants and Dementia Champions echoed how DF participants felt their confidence grow through learning concrete skills and the importance of patience and understanding when interacting with someone with dementia. This confidence appeared to spark a call to action, inspiring both DF participants and Dementia Champions to find ways to implement what they learned into practice, which persisted over time.

DF participants and Dementia Champions both spoke of how the interactions as a group helped DF participants integrate what they learned to their personal lives. This was further evidenced in our quantitative findings, showing significant differences in impact across DF session based on which trainer hosted the DF session. Davison et. al. (2019) also found that DF

participants enjoy the group setting, having an opportunity to share and develop relationships, while also learning about another view on dementia.

## **4.2 Implementation**

Our study identified several factors that influence the implementation of the DF program: the individual Champion characteristics, organizational support for Champions, content of DF sessions, and accessibility of DF sessions. Champions with little experience giving presentations or those with limited time struggled to organize their DF sessions. This finding echoes other studies looking at train-the-trainer models, which found that trainers face difficulties navigating scheduling, conflicting responsibilities, and different levels of confidence all leading to challenges remaining involved in the programs (Anderson & Taira, 2018; Bale & Jenkins, 2018; Wittenberg et. al., 2020).

The study also revealed the importance of organizational support for Champions. For this study, the majority of materials and supplies were provided by the Master Champion through local sponsorship, with additional materials delivered to the Dementia Champions whenever needed. The Dementia Champions commented on how these resources made a difference in their ability to organize and host a DF session. Having the necessary resources available for trainers in similar train-the-trainer programs, particularly when asking community members to assume a significant role with no compensation, has been identified as a significant facilitator in other studies as well (Anderson & Taira, 2018).

Dementia Champions also suggested enhancing the content of the DF session so that persons with dementia and/or their care-partners would be included more directly, either through videos, a written passage, or through being a Dementia Champion. Hayashi (2017) discussed this need for more meaningful integration of persons with dementia into DF sessions in order to truly

be following the key dementia advocacy principle of “nothing about us, without us”. One example of this meaningful integration came from Phillipson et. al. (2019) where a Dementia Friendly pilot worked with dementia advocacy groups made of persons with dementia and their care-partners to create a materials and activities to increase community awareness in their community. Having persons with dementia and their care-partners facilitating and designing the materials demonstrated the strengths and abilities of persons with dementia and assured a deep connection to the lived reality of having dementia through the educational program.

### **4.3 Limitations**

There were several study limitations. While the Dementia Champions brought both racial and experiential diversity, there was limited racial and gender diversity of DF participants, which limits the generalizability of the study findings to other geographic areas. Additionally, each DF session had little oversight or monitoring to confirm fidelity across DF sessions. However, in the implementation of this program, we wanted to keep the program as true to its natural implementation, relying on the materials and the script that Champions are told to follow closely to maintain fidelity. An additional limitation is that due to the first author implementing the DF program while also collecting and analyzing the data, there may be confirmation bias. To combat this our research process included soliciting and integrating feedback from researchers and community stakeholders regularly, in addition to consulting with a second coder for the interviews.

### **4.5 Dissemination**

Based on studies conducted so far, the next step is to implement the recommendations to bolster Dementia Champions’ support and actively disseminate the Dementia Friends program. Harris et. al. (2012) created a framework for disseminating evidence-based programs. The

framework suggests first creating relationships with organizations interested in supporting dissemination. From there, researchers and the disseminating organizations work together to strategize the best way to spread the program given the available resources, capacity, and evidence. Together, they can recruit organizations interested in adopting the program, assessing the interested organizations for their readiness to support adoption, implementation, and maintenance of the program.

In Washington, the Dementia Action Collaborative, a private-public partnership working to implement the Washington State Plan to Address Alzheimer's and Other Dementias, in partnership with Harborview's Memory and Brain Wellness Center (MBWC) are modeling this example. Currently, MBWC is recruiting Regional Lead Organizations that take responsibility for disseminating the DF program in their region (defined as county or tribe). The Regional Lead Organization identifies a Master Champion who recruits, trains and manages local DF Champions. MBWC trains the Master Champion and provides technical assistance as needed in developing a sustainable program framework and recruiting, training and supporting Dementia Champions. This model appears to be effective and allows the program to have sustainability as it grows, while keeping the programs grounded in the local community's needs. We believe that the current study will help further dissemination of DF by providing further insight into what worked well and what should change for an impactful DF program.

## **5. CONCLUSION**

This study of the Dementia Friends program showed that Dementia Friends is an important and effective program, helping to change the attitudes and stigma that surround dementia. The group atmosphere and facilitation by Dementia Champions created community

within the DF sessions, which deepened DF participant's experience and interest in the DF session.

Future research should investigate the impact of DF sessions in different settings (offices, homes, etc.) and more diverse populations. Researchers should also explore how more comprehensive training contributes to Dementia Champion's ability to organize and host sessions. Future efforts should also focus on a wider dissemination of the program to expand its reach in Washington State and beyond. However, in the dissemination process it will be important to listen to the experiences and advice given by the Champions in this study to create a sustainable and supportive experience for Champions and participants alike.

## 6. References

- Alzheimer's Association. (2020). Alzheimer's Disease Facts and Figures. *Alzheimer's Disease and Dementia*, 16(3). Retrieved March 29, 2020, from <https://www.alz.org/alzheimers-dementia/facts-figures>
- Alzheimer's Disease International. (2015). *World Alzheimer Report 2015, The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
- Anderson, C. R., & Taira, B. R. (2018). The train the trainer model for the propagation of resuscitation knowledge in limited resource settings: A systematic review. *Resuscitation*, 127, 1–7. <https://doi.org/10.1016/j.resuscitation.2018.03.009>
- Annear, M. J., Toye, C. M., Eccleston, C. E., McInerney, F. J., Elliott, K.-E. J., Tranter, B. K., Hartley, T., & Robinson, A. L. (2015). Dementia Knowledge Assessment Scale: Development and Preliminary Psychometric Properties. *Journal of the American Geriatrics Society*, 63(11), 2375–2381. <https://doi.org/10.1111/jgs.13707>
- Annear, M. J., Toye, C., Elliott, K.-E. J., McInerney, F., Eccleston, C., & Robinson, A. (2017). Dementia knowledge assessment scale (DKAS): Confirmatory factor analysis and comparative subscale scores among an international cohort. *BMC Geriatrics*, 17(1), 168. <https://doi.org/10.1186/s12877-017-0552-y>
- Baillie, L., Beecraft, S., & Woods, S. (2015). Dementia Friends Sessions for Nursing Students. *Nursing Older People*, 27(9), 34–38. Scopus. <https://doi.org/10.7748/nop.27.9.34.s20>
- Bale, L., & Jenkins, C. (2018). Nursing students' experiences of delivering dementia friends sessions to peers. *Nursing Older People*, 30(6). Scopus. <https://doi.org/10.7748/nop.2018.e1046>

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Cowan, T. L. (2019). College students' and community members' attitudes toward dementia: The impact of dementia friends sessions. *Gerontology & Geriatrics Education*, 1–10.  
<https://doi.org/10.1080/02701960.2019.1657859>
- Davison, E., Housden, S., & Lindqvist, S. (2019). Using interprofessional dementia learning opportunities to prepare the future healthcare workforce: Findings from a pilot study. *Journal of Interprofessional Care*, 33(6), 816–819. <https://doi.org/10.1080/13561820.2018.1551863>
- “Dementia friends” scheme will need more resources, says RCN. (2012). *Nursing Standard*, 27(11).
- George, D. R., Stuckey, H. L., & Whitehead, M. M. (2014). How a creative storytelling intervention can improve medical student attitude towards persons with dementia: A mixed methods study. *Dementia*, 13(3), 318–329. <https://doi.org/10.1177/1471301212468732>
- Gibson, C., Rennie, K., Dewing, J., & McKinlay, L. (2018). Developing facilitation skills amongst undergraduate nursing students to promote dementia awareness with children in a higher education institution (innovative practice). *Dementia*, 1471301218811788.  
<https://doi.org/10.1177/1471301218811788>
- Harris, J. R., Cheadle, A., Hannon, P. A., Lichiello, P., Forehand, M., Mahoney, E., Snyder, S., & Yarrow, J. (2012). A framework for disseminating evidence-based health promotion practices. *Preventing Chronic Disease*, 9.
- Hayashi, M. (2017). The Dementia Friends initiative - supporting people with dementia and their carers: Reflections from Japan. *International Journal of Care and Caring*, 1(2), 281–287.  
<https://doi.org/10.1332/239788217X14951898377524>

- Hebert, C. A., & Scales, K. (2019). Dementia friendly initiatives: A state of the science review. *Dementia*, 18(5), 1858–1895. <https://doi.org/10.1177/1471301217731433>
- Hsieh, H., & Shannon, S. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Kimzey, M., Mastel-Smith, B., & Alfred, D. (2016). The impact of educational experiences on nursing students' knowledge and attitudes toward people with Alzheimer's disease: A mixed method study. *Nurse Education Today*, 46, 57–63. <https://doi.org/10.1016/j.nedt.2016.08.031>
- Mitchell, G., McGreevy, J., Carlisle, S., Frazer, P., Traynor, M., Lundy, H., Diamond, M., & Agnelli, J. (2017). Evaluation of 'Dementia Friends' programme for undergraduate nursing students: Innovative practice. *Dementia*, 16(8), 1075–1080. <https://doi.org/10.1177/1471301216638589>
- O'Connor, M. L., & McFadden, S. H. (2010). Development and Psychometric Validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*. <https://doi.org/10.4061/2010/454218>
- Phillipson, L., Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., Frost, D., & Hasan, H. (2019). Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia*, 18(7–8), 2679–2694. <https://doi.org/10.1177/1471301218754455>
- R Core Team (2019). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL <https://www.R-project.org/>.
- Tessier, A., Power, E., & Croteau, C. (2020). Paid worker and unfamiliar partner communication training: A scoping review. *Journal of Communication Disorders*, 83, 105951. <https://doi.org/10.1016/j.jcomdis.2019.105951>

World Health Organization (WHO). (2019, September 19). Dementia. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>

Woods, S. (2017, June 19). *Explore the lived experience of Dementia Friends Champions: Poetic representation*. Royal College of Occupational Therapists, Birmingham. <https://openresearch.lsbu.ac.uk/item/86yzw>

## 7. TABLES

Table 1: Demographic Data

Demographics		Dementia Champion		Dementia Friend Participant	
		Total (N=15)	Percent (%)	Total (N=214)	Percent (%)
<b>Gender</b>	<i>Woman</i>	13	87%	147	71%
	<i>Man</i>	2	13%	56	27%
	<i>Gender queer, non-binary, or gender expansive</i>	0	0%	5	2%
	<b>TOTAL</b>	15	100%	208	100%
<b>Race</b>	<i>White</i>	8	53%	162	81%
	<i>Hispanic or Latino(a)</i>	1	7%	17	8%
	<i>Black or African American</i>	4	27%	6	3%
	<i>Asian or Asian American</i>	0	0%	9	4%
	<i>Native Hawaiian/Pacific Islander</i>	0	0%	1	0%
	<i>American Indian, Alaska Native</i>	2	13%	2	1%
	<i>Mixed Race</i>	0	0%	4	2%
	<b>TOTAL</b>	15	100%	201	100%
<b>Age</b>	<i>18-30</i>	2	13%	43	21%
	<i>31-45</i>	4	27%	33	16%
	<i>46-65</i>	5	33%	51	25%
	<i>66-79</i>	4	27%	52	26%
	<i>80+</i>	0	0%	23	11%
	<b>TOTAL</b>	15	100%	202	100%
	<b>Employment</b>	<i>Retired</i>	2	13%	74
<i>Not Currently Employed</i>		0	0%	3	2%
<i>Student</i>		2	13%	48	23%

	<i>Work full-time</i>	9	60%	51	25%
	<i>Work part-time</i>	2	13%	24	12%
	<i>Other</i>	0	0%	7	2%
	<b>TOTAL</b>	15	100%	207	100%
<b>Experience with Dementia</b>	<i>I am a person with dementia</i>	0	0%	2	1%
	<i>Informal Care-partner</i>	3	20%	26	13%
	<i>Formal Care-partner</i>	2	13%	15	7%
	<i>I have family, friends, or acquaintances with dementia</i>	3	20%	68	33%
	<i>I have no prior connection to persons with dementia</i>	0	0%	43	21%
	<i>Multiple Connections</i>	7	47%	42	21%
	<i>Other</i>	0	0	8	4%
	<b>TOTAL</b>	15	100%	204	100%
<b>Education</b>	<i>Less than high school</i>	0	0%	4	2%
	<i>High School or GED</i>	2	13%	21	10%
	<i>Less than 4 years of college</i>	3	20%	56	27%
	<i>4-year college degree</i>	4	27%	49	24%
	<i>More than 4 years of college (master's degree of higher)</i>	6	40%	78	38%
	<b>TOTAL</b>	15	100%	208	100%
<b>Location</b>	<i>Urban</i>	10	67%	103	50%
	<i>Rural</i>	5	33%	102	50%
	<b>TOTAL</b>	15	100%	205	100%
<b>DAS Scores</b>		<i>Comfort</i>	<i>Knowledge</i>	<i>Comfort</i>	<i>Knowledge</i>
	<i>Pre-survey</i>	5.5	6.2	4.6	5.9
	<i>Post Survey</i>	5.6	6.5	5.3	6.2
	<i>1-month Post Survey</i>	N/A	N/A	5.2	6.3

Table 2: DF Participant Responses on Value, Strengths, Weaknesses, and Redesign of DF Session from Post-Session Survey

DF Participant Post-Session Survey Responses		
What is the most valuable thing you learned today (knowledge or skills)?	% (count)	Example Quote
How to Better Communicate with Persons with Dementia (PWD)	33% (59)	“Respectful tactics I can implement in my day to day life/interactions with people with or without dementia”

Knowledge about Dementia	24% (44)	"Understanding that dementia is not just a memory issue, it's about communication as well."
Patience and understanding	21% (37)	"I learned how to be more patient and understanding not only to people with dementia, but to people in general."
How to Support PWD	12% (22)	"There are easy ways to help people with dementia."
Strengths of PWD	9% (17)	"Creative & sensitive nature of many people with ADRD"
<b>Grand Total</b>	<b>179</b>	
<b>What do you feel were the strengths of this information session?</b>	<b>% (count)</b>	<b>Example Quote</b>
Clarity and Quality of Content on Dementia	33% (60)	"Clear points, good repetition, great handouts, good balance of talking and audience participation"
Presenter Knowledge and Skills	22% (40)	"The experience the presenters had in the field made it easier for me to relate, and better able to help my grandma."
Built Empathy and Understanding	15% (27)	"Emphasis on compassion and a respect for personal dignity, as well as the perspective of what it would be like to have dementia"
Communication tips	11% (20)	"How to treat people with dementia...how to treat my father in a helpful way"
Informal Community Atmosphere	10% (19)	"Getting people together to talk about it and learn together, building community"
Other	10% (18)	N/A
<b>Grand Total</b>	<b>184</b>	
<b>What do you feel were the weaknesses of this information session?</b>	<b>% (count)</b>	<b>Example Quote</b>
Too general	42% (58)	"There could have been more medical/scientific information about how dementia effects the brain."
Nothing	41% (56)	N/A
Venue (size, acoustics)	7% (9)	"Set up of room was not the best, hard to hear and see participant."
Presenter Knowledge and Skills	7% (9)	"Reading...is never the best teaching method but it was done with grace. Perhaps more examples compared to verbatim recitation."
Other	4% (6)	N/A
<b>Grand Total</b>	<b>138</b>	
<b>If you were given the task of redesigning the workshop, what would you change?</b>	<b>% (count)</b>	<b>Example Quote</b>
Nothing	46% (62)	N/A
More time to practice skills	10% (13)	"Maybe practicing some of the 'hands-on' suggestions. I think this was the most useful part of the talk and it was only brought up in the last 5-10 minutes."
More specific information on dementia disease	18% (24)	"Maybe give more background info about the disease in terms of prevalence, causes, etc."

More time for participants to share stories	6% (8)	"More interaction perhaps between participants."
Improve Venue	6% (8)	"Larger room or decreased number of people in attendance."
Other	14% (19)	N/A
<b>Grand Total</b>	<b>134</b>	

*Table 3: DF Participant Responses on Meaning, Importance, and Redesign Ideas for DF Session from Post-Session Survey*

<b>DF Participant 1-Month Post-Session Survey Responses</b>		
<b>What was meaningful to you about this experience?</b>	<b>% (count)</b>	<b>Example Quote</b>
Knowledge about Dementia	32% (25)	"How there is more to dementia than I thought."
Patience and understanding	28% (22)	"I've kept in mind the idea of managing my energy when I'm with someone living with dementia. I have less fear around dementia."
How to Support PWD	23% (18)	"Putting things I've learned into actions has helped me be a better care giver. Understanding why the person with dementia is acting a certain way helps me to help him deal with it better."
Supportive Group Environment	14% (11)	"I appreciated the welcoming and safe environment when discussing how to best support individuals part of the dementia community."
Other	4% (3)	N/A
<b>Grand Total</b>	<b>79</b>	
<b>Do you think this program is worthwhile to expand across Washington State? Why or why not?</b>	<b>% (count)</b>	<b>Example Quote</b>
Expanded knowledge about and compassion for people with dementia	40% (35)	"Yes! This is an issue that people do not know enough about or have enough access to information about. I thought I had a good understanding of what [dementia] was before the workshop, but afterwards realized how many things I was uncomfortable with or did not understand about people experiencing it in their lives."
There is a growing need for people who can understand and support people with dementia	32% (28)	"Yes, I believe that many people in our state do not understand dementia and how to cope with it."
Important support for current and future care-partners	16% (14)	"Yes, I am better equipped to deal with my mother and I think other families would benefit."
Other	11% (10)	N/A
<b>Grand Total</b>	<b>87</b>	
<b>If you were given the task of redesigning the workshop, what would you change?</b>	<b>% (count)</b>	<b>Example Quote</b>
More specific information about dementia	44% (15)	"More substantive issues should be addressed: identifying the kinds of help and support that is needed; knowing when it is time to consider full-time professional care at home or in a care facility; recognizing the subtle changes and decline in dementia."

More time for participants to share stories	21% (7)	“More time for questions at the end. More personal stories to connect the facts with experience”
Provide ongoing support/resources	12% (4)	“I would provide more actual resources; websites, state, local & federal programs, respite care options, etc.”
Other	24% (11)	N/A
<b>Grand Total</b>	<b>34</b>	

Table 4: Commitment to Take Action

Turn Understanding into Action	# of Post-Session Responses (n=180)	%	# 1-month Post-Session Responses (n=101)	%
Support dementia friendly efforts in my community	99	55%	28	28%
Carry out a personal action e.g. being more patient when out in my community	98	54%	46	46%
Encourage friends to become Dementia Friends	80	44%	28	28%
Adopt 1 or more dementia friendly practices in my personal or professional life	80	44%	29	29%
Get in touch and stay in touch with someone I know living with dementia	70	39%	32	32%
Ask my doctor for cognitive assessment during my annual physical exam	32	18%	3	3%
Volunteer for an organization that helps people with dementia	24	13%	7	7%
Volunteer to participate in a clinical trial	22	12%	1	1%
Other	15	8%	8	8%
Campaign for change, e.g. by participating in local advocacy events	14	8%	3	3%
Start a dementia friendly effort in my community	9	5%	0	0%

Table 5: Implementation Post-Session Survey Accessibility Responses

Implementation Survey Questions	Excellent, % (count)	Good, % (count)	Neutral, % (count)	Fair, % (count)	Poor, % (count)
How was your overall information session experience? (N=205)	83% (170)	17% (35)	0% (0)	0% (0)	0% (0)
Do you think that the information presented was easy to understand? (N=206)	88% (181)	12% (25)	0% (0)	0% (0)	0% (0)
Were you able to clearly hear and see the speaker? (N=202)	90% (181)	8% (17)	0% (0)	0% (3)	0% (1)
Speakers Expertise (N=204)	77% (158)	22% (45)	0% (1)	0% (0)	0% (0)
Speaker's Clarity (N=204)	85% (174)	12% (29)	0% (0)	0% (1)	0% (0)
Speaker's Cultural Appropriateness (N=203)	82% (166)	15% (30)	0% (7)	0% (0)	0% (0)

<i>Speaker's Time Management (N=204)</i>	78% (160)	21% (43)	0% (0)	0% (1)	0% (0)
<i>Speaker's Responsiveness (N=200)</i>	91% (182)	9% (18)	0% (0)	0% (0)	0% (0)

Table 6: Suggestions for Program Alterations

Area of Change	Suggested Program Alterations
<i>DF Content</i>	No survey, or a shorter survey
	More detailed clinical information about dementia in the session
	More time to practice skills discussed in DF session
	More time for questions and interactions across participants
<i>DF Implementation</i>	Maintain and increase the diversity of Champions
	Assess Champion capacity and need for specific supports before they begin this volunteer position
	Increase amount of time in Champion training for practicing giving the DF session
	Add time in Champion training on tips for giving a presentation, hosting a talk, setting up a space, explaining the purpose of the talk, and how to manage time
	Provide tips on how to recruit participants, including template for flyers, emails, social media posts
	Provide Champions with a script to answer frequent questions
	Create list of locations willing to be venues for DF sessions, including contact information
	Increase community building opportunities for Champions to gather and get advice and support from one-another

Table 7: Individual Question DAS Scores

Item		Pre-Survey Mean $\pm$ SD	Post-Survey Mean $\pm$ SD	1-Month Post-Survey Mean $\pm$ SD	Difference in Mean (post-pre)	p-value	Difference in Mean (1-month post-pre)	p-value
<b>Individual Items</b>	1. It is rewarding to work with people who have Alzheimer disease and related dementias (ADRD).	5.9 $\pm$ 1.3	5.9 $\pm$ 1.0	5.6 $\pm$ 1.2	0.74	<0.001	0.39	<0.001
	2. I am afraid of people with ADRD.	5.6 $\pm$ 1.6	5.9 $\pm$ 1.2	6.1 $\pm$ 1.1	0.35	0.001	0.77	<0.001

3. People with ADRD can be creative.	5.6 ± 1.3	6.2 ± 1.0	6.4 ± 0.9	0.55	<0.001	0.67	<0.001
4. I feel confident around people with ADRD.	4.6 ± 1.6	5.4 ± 1.3	5.3 ± 1.3	0.88	<0.001	0.81	<0.001
5. I am comfortable touching people with ADRD.	5.1 ± 1.6	5.5 ± 1.4	5.4 ± 1.5	0.34	<0.001	0.15	0.23
6. I feel uncomfortable being around people with ADRD.	4.9 ± 1.8	5.3 ± 1.7	5.5 ± 1.6	0.42	0.007	0.62	0.001
7. Every person with ADRD has different needs.	6.4 ± 1.0	6.5 ± 1.0	6.6 ± 0.6	0.15	0.07	0.12	0.19
8. I am not very familiar with ADRD.	3.7 ± 2.0	5.3 ± 1.5	5.3 ± 1.5	1.56	<0.001	1.48	<0.001
9. I would avoid an agitated person with ADRD.	3.6 ± 1.7	4.4 ± 1.7	4.2 ± 1.8	0.87	<0.001	0.80	<0.001
10. People with ADRD like having familiar things nearby.	5.9 ± 1.2	6.3 ± 0.9	6.3 ± 0.8	0.42	<0.001	0.42	<0.001
11. It is important to know the past history of people with ADRD.	5.6 ± 1.4	5.6 ± 1.6	5.8 ± 1.2	0.04	0.69	-0.04	0.76
12. It is possible to enjoy interacting with people with ADRD.	6.0 ± 1.2	6.3 ± 0.7	6.3 ± 1.0	0.36	<0.001	0.12	0.29
13. I feel relaxed around people with ADRD.	4.6 ± 1.5	5.2 ± 1.2	5.0 ± 1.4	0.63	<0.001	0.45	<0.001
14. People with ADRD can enjoy life.	5.9 ± 1.1	6.3 ± 0.8	6.3 ± 0.9	0.52	<0.001	0.36	<0.001
15. People with ADRD can feel when others are kind to them.	6.1 ± 1.0	6.6 ± 0.7	6.5 ± 0.8	0.49	<0.001	0.13	0.15
16. I feel frustrated because I do not know how to help people with ADRD.	3.6 ± 1.6	5.1 ± 1.4	4.8 ± 1.5	1.47	<0.001	1.18	<0.001
17. I cannot imagine caring for someone with ADRD.	4.6 ± 1.8	5.1 ± 1.7	5.1 ± 1.7	0.61	<0.001	0.58	<0.001
18. I admire the coping skills of people with ADRD.	5.5 ± 1.2	6.0 ± 1.1	5.9 ± 1.1	0.53	<0.001	0.31	0.02
19. We can do a lot now to improve the	5.9 ± 1.2	6.4 ± 0.7	6.3 ± 1.0	0.60	<0.001	0.45	<0.001

	lives of people with ADRD.							
	20. Difficult behaviors may be a form of communication for people with ADRD.	5.7 ± 1.2	6.4 ± 0.8	6.2 ± 1.1	0.72	<0.001	0.26	<0.001
<b>Subcategories</b>	Comfort (items 1, 2, 4, 5, 6, 8, 9, 13, 16, 17)	4.6 ± 1.1	5.3 ± 0.8	5.2 ± 1.1	0.79	<0.001	0.72	<0.001
	Knowledge (items 3, 7, 10, 11, 12, 14, 15, 18, 19, 20)	5.8 ± 0.8	6.2 ± 0.7	6.3 ± 0.7	0.41	<0.001	0.28	<0.001
<b>Overall DAS</b>		5.2 ± 0.8	5.8 ± 0.8	5.8 ± 0.7	0.60	<0.001	0.56	<0.001

## 8. APPENDIX

### 8.1 DF Participants' Pre-Session Survey



## Dementia Friends Pre-Session Survey

Thank you for participating in our evaluation of Dementia Friends Washington. Before starting your information session to become a Dementia Friend, we ask that you complete this survey. This survey takes about 10 minutes to complete and your responses are completely voluntary. You will also be asked to complete a survey after this information session and another survey by email one month after you attend your Dementia Friend information session. Once you complete that final survey, we will enter your name in a raffle to win a \$100 gift card.

**To maintain privacy, your contact information will be detached and stored separately from the rest of the questionnaire. We are asking for your contact information for our internal use only. We will not be sharing this information with others. We would like to contact you at the completion of the project to solicit your input and send you final results of our project at the end of 2019. Please let us know if you have any concerns or questions.**

If you have any questions or need assistance completing this survey, please email the Dementia Friends Washington team at [dementiafriendswa@gmail.com](mailto:dementiafriendswa@gmail.com).

**Preferred Name:**

**Pronouns:**

**Address:**

**Phone Number:**

**Primary Email Address:**

**What Dementia Friends information session are you attending today?**

Date:

Time:

Location:

Presenter's Name:

**We would like to ask you about your thoughts about dementia.**

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

	<i>Statements</i>	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Slightly Disagree</i>	<i>Neutral</i>	<i>Slightly Agree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1.	It is rewarding to work with people who have ADRD.	1	2	3	4	5	6	7
2.	I am afraid of people with ADRD.	1	2	3	4	5	6	7
3.	People with ADRD can be creative.	1	2	3	4	5	6	7
4.	I feel confident around people with ADRD.	1	2	3	4	5	6	7
5.	I am comfortable touching people with ADRD.	1	2	3	4	5	6	7
6.	I feel uncomfortable being around people with ADRD.	1	2	3	4	5	6	7
7.	Every person with ADRD has different needs.	1	2	3	4	5	6	7
8.	I am not very familiar with ADRD.	1	2	3	4	5	6	7
9.	I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
10.	People with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
11.	It is important to know the past history of people with ADRD.	1	2	3	4	5	6	7

12.	It is possible to enjoy interacting with people with ADRD.	1	2	3	4	5	6	7
13.	I feel relaxed around people with ADRD.	1	2	3	4	5	6	7
14.	People with ADRD can enjoy life.	1	2	3	4	5	6	7
15.	People with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
16.	I feel frustrated because I do not know how to help people with ADRD.	1	2	3	4	5	6	7
17.	I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
18.	I admire the coping skills of people with ADRD.	1	2	3	4	5	6	7
19.	We can do a lot now to improve the lives of people with ADRD.	1	2	3	4	5	6	7
20.	Difficult behaviors may be a form of communication for people with ADRD.	1	2	3	4	5	6	7

**Next, we would like to learn about your experience around dementia.**

1. How knowledgeable are you about dementia? **[check only one]**
  - To a great extent
  - Somewhat
  - Very little
  - Not at all
  
2. Have you ever received formal education about dementia before (ex/: attended a training or a class, researched on your own)? **[check only one]**
  - Yes
  - No
  - If yes, where? \_\_\_\_\_
  
3. What experience do you have with persons with dementia? **[check all that apply]**
  - I am a person with dementia
  - I provide care for a loved one with dementia
  - I provided care for a loved one with dementia in the past
  - I work with persons with dementia
  - I have family, friends or acquaintances with dementia
  - I have no prior connection to persons with dementia
  - Other: \_\_\_\_\_
  
4. Why did you sign-up for this Dementia Friends information session? **[check all that apply]**
  - A friend/family member is running this information session
  - I have a personal connection to dementia
  - I want to learn more about dementia
  - I want to be more involved in my community
  - Other (please specify): \_\_\_\_\_
  
5. Anything else you want to add?

**Finally, we would like to ask some questions about you.**

2. What year were you born?  
\_\_\_\_\_
  
3. What is your zip code?  
\_\_\_\_\_
  
4. What is your employment status? **[check all that apply]**

- Retired
- Not currently employed
- Student
- Work full-time (30 or more paid hours a week)
- Work part-time (less than 30 paid hours a week)
- Other: \_\_\_\_\_

5. Which of the following would you use to describe yourself? **[check all that apply]**

- White
- Hispanic or Latino(a)
- Black or African American
- Asian or Asian American
- Native Hawaiian/ Pacific Islander
- American Indian, Alaskan Native
- Not listed above (please specify) \_\_\_\_\_

6. Which of the following best represents your current gender? **[check only one]**

- Woman
- Man
- Gender queer or non-binary or gender expansive
- Not listed above (please specify) \_\_\_\_\_

7. What is the highest level of education you have completed? **[check only one]**

- Less than high school
- High school or GED
- Less than 4 years of college
- 4-year college degree
- More than 4 years of college (master's degree or higher)

8. We would welcome any additional comments!

## 8.2 DF Participants' Post-Session Survey



# Dementia Friends Post-Session Survey

Thank you for attending this Dementia Friends Washington information session! Now that you have attended this session, we ask that you complete this survey to help with our evaluation of this program. This survey takes about 10 minutes to complete and your responses are completely voluntary. You will also be asked to complete a survey by email/phone one month after you attend your Dementia Friend information session. Once you complete that final survey, we will enter your name in a raffle to win a \$100 gift card.

**To maintain privacy, your contact information will be detached and stored separately from the rest of the questionnaire. We are asking for your contact information for our internal use only. We will not be sharing this information with others. We would like to contact you at the completion of the project to solicit your input and send you final results of our project at the end of 2019. Please let us know if you have any concerns or questions.**

If you have any questions or need assistance completing this survey, please email the Dementia Friends Washington team at [dementiafriendswa@gmail.com](mailto:dementiafriendswa@gmail.com).

**Preferred Name:**

**Pronouns:**

**Address:**

**Phone Number:**

**Primary Email Address:**

**We would like to ask you a bit about your thoughts about dementia.**

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong*

answers. The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

	<i>Statements</i>	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Slightly Disagree</i>	<i>Neutral</i>	<i>Slightly Agree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1.	It is rewarding to work with people who have ADRD.	1	2	3	4	5	6	7
2.	I am afraid of people with ADRD.	1	2	3	4	5	6	7
3.	People with ADRD can be creative.	1	2	3	4	5	6	7
4.	I feel confident around people with ADRD.	1	2	3	4	5	6	7
5.	I am comfortable touching people with ADRD.	1	2	3	4	5	6	7
6.	I feel uncomfortable being around people with ADRD.	1	2	3	4	5	6	7
7.	Every person with ADRD has different needs.	1	2	3	4	5	6	7
8.	I am not very familiar with ADRD.	1	2	3	4	5	6	7
9.	I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
10.	People with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
11.	It is important to know the past history of people with ADRD.	1	2	3	4	5	6	7
12.	It is possible to enjoy interacting with people with ADRD.	1	2	3	4	5	6	7

13	I feel relaxed around people with ADRD.	1	2	3	4	5	6	7
14	People with ADRD can enjoy life.	1	2	3	4	5	6	7
15	People with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
16	I feel frustrated because I do not know how to help people with ADRD.	1	2	3	4	5	6	7
17	I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
18	I admire the coping skills of people with ADRD.	1	2	3	4	5	6	7
19	We can do a lot now to improve the lives of people with ADRD.	1	2	3	4	5	6	7
20	Difficult behaviors may be a form of communication for people with ADRD.	1	2	3	4	5	6	7

Now, we would like to hear about what you thought of this information session.

6. What Dementia Friends information session did you attend?

Date:

Time:

Location:

Presenter's Name:

7. How was your overall information session experience?

Excellent

Good

Fair

Poor

8. Did you think that the information presented was easy to understand?

Excellent

Good

Fair

Poor

9. Were you able to clearly hear and see the speaker?

Excellent

Good

Fair

Poor

10. Please rate this training in terms of the **Speaker's Expertise, Clarity, Cultural Appropriateness, Time Management, and Responsiveness** to your needs. 1 is poor, 2 is fair, 3 is neutral, 4 is good, 5 is excellent. Circle the appropriate numbers.

<b>How was the speaker's:</b>	<i>Poor</i>	<i>Fair</i>	<i>Neutral</i>	<i>Good</i>	<i>Excellent</i>
<b>Expertise</b>	1	2	3	4	5
<b>Clarity</b>	1	2	3	4	5
<b>Cultural Appropriateness</b>	1	2	3	4	5
<b>Time Management</b>	1	2	3	4	5
<b>Responsiveness</b>	1	2	3	4	5

11. What is the most valuable thing you learned today (knowledge or skills)?

12. What do you feel were the strengths of this information session?

13. What do you feel were the weaknesses of this information session?

14. If you were given the task of redesigning the workshop, what would you change?

15. Additional comments about the information session?

**Finally, turn your understanding into ACTION.**

16. As a Dementia Friend, I will... (select at least one)

- Get in touch and stay in touch with someone I know living with dementia
- Support dementia friendly efforts in my community
- Start a dementia friendly effort in my community
- Volunteer for an organization that helps people with dementia
- Campaign for change, e.g. by participating in local advocacy events
- Encourage friends to become Dementia Friends
- Carry out a personal action e.g. being more patient when out in my community
- Volunteer to participate in a clinical trial
- Adopt 1 or more dementia friendly practices in my personal or professional life
- Ask my doctor for cognitive assessment during my annual physical exam
- Other: \_\_\_\_\_

17. We would welcome any additional thoughts or feedback!

### 8.3 DF Participants' 1-Month Post-Session Survey



## 1-Month Post-Session Survey

Hello Dementia Friends!

About a month ago you attended a Dementia Friends talk where you learned about dementia, the ways dementia impacts people's health, and chose a small action step you'd like to take. Thank you so much for coming to that talk and helping us create more supportive communities for people with dementia! As your presenter mentioned, this talk was part of an evaluation of the Dementia Friends program. For the final part of this evaluation, we are asking you to complete this 15-minute survey to tell us more about your thoughts on the program.

To maintain privacy, your contact information will be detached and stored separately from the rest of the questionnaire. We are asking for your contact information for our internal use only. We will **not** be sharing this information with others.

Please return this completed survey in the enclosed postage-paid envelope as soon as you can. If the enclosed postage-paid envelope is missing, please mail it to: Dementia Friends WA, 325 9th Ave, Seattle, WA 98104.

**Once you complete this survey and mail it back to us, we will enter your name in a raffle to win a \$100 gift card.**

*If you have any questions or need assistance completing this survey, please contact us by phone (xxx) xxx-xxxx or email at [dementiafriendswa@gmail.com](mailto:dementiafriendswa@gmail.com). We are tremendously grateful for you taking the time to help us in this project!*

**Full Name:**

**Preferred Contact Information:**

**First, we would like to ask you a bit about your thoughts about dementia.**

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym "ADRD" in each question stands for "Alzheimer's disease and related dementias."

	<i>Statements</i>	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Slightly Disagree</i>	<i>Neutral</i>	<i>Slightly Agree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1.	It is rewarding to work with people who have ADRD.	1	2	3	4	5	6	7
2.	I am afraid of people with ADRD.	1	2	3	4	5	6	7
3.	People with ADRD can be creative.	1	2	3	4	5	6	7
4.	I feel confident around people with ADRD.	1	2	3	4	5	6	7
5.	I am comfortable touching people with ADRD.	1	2	3	4	5	6	7
6.	I feel uncomfortable being around people with ADRD.	1	2	3	4	5	6	7
7.	Every person with ADRD has different needs.	1	2	3	4	5	6	7
8.	I am not very familiar with ADRD.	1	2	3	4	5	6	7
9.	I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
10.	People with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
11.	It is important to know the past history of people with ADRD.	1	2	3	4	5	6	7
12.	It is possible to enjoy interacting with people with ADRD.	1	2	3	4	5	6	7

13.	I feel relaxed around people with ADRD.	1	2	3	4	5	6	7
14.	People with ADRD can enjoy life.	1	2	3	4	5	6	7
15.	People with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
16.	I feel frustrated because I do not know how to help people with ADRD.	1	2	3	4	5	6	7
17.	I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
18.	I admire the coping skills of people with ADRD.	1	2	3	4	5	6	7
19.	We can do a lot now to improve the lives of people with ADRD.	1	2	3	4	5	6	7
20.	Difficult behaviors may be a form of communication for people with ADRD.	1	2	3	4	5	6	7

**Now, we would like to hear about your experience with dementia since your training.**

18. After the training, what action step did you commit to taking? (If you do not remember, please select “Not sure”)

- Get in touch and stay in touch with someone I know living with dementia
- Support dementia friendly efforts in my community
- Start a dementia friendly effort in my community
- Volunteer for an organization that helps people with dementia
- Campaign for change, e.g. by participating in local advocacy events
- Encourage friends or family members to become Dementia Friends
- Carry out a personal action e.g. being more patient when out in my community
- Volunteer to participate in a clinical trial
- Adopt 1 or more dementia friendly practices in my personal or professional life

- Ask my doctor for cognitive assessment during my annual physical exam
- Other, please specify:
- Not sure

19. Were you able to complete that action?

- Yes
- No

20. If not, were you able to complete a different action? [CHECK ALL THAT APPLY]

- Get in touch and stay in touch with someone I know living with dementia
- Support dementia friendly efforts in my community
- Start a dementia friendly effort in my community
- Volunteer for an organization that helps people with dementia
- Campaign for change, e.g. by participating in local advocacy events
- Encourage friends or family members to become Dementia Friends
- Carry out a personal action e.g. being more patient when out in my community
- Volunteer to participate in a clinical trial
- Adopt 1 or more dementia friendly practices in my personal or professional life
- Ask my doctor for cognitive assessment during my annual physical exam
- Other, please specify:

21. Did anything **prevent** you from completing your chosen action? [CHECK ALL THAT APPLY]

- Personal events
- Lack of access to information to get involved in action
- Fitting it into my schedule
- It was too ambitious for my schedule
- Inhibition to try something new
- I forgot about it
- Other, please specify:

22. What **helped** you work on your chosen action? [CHECK ALL THAT APPLY]

- Support from others
- Personal connection to dementia
- Having available time
- Having access to resources (ex/: transportation, information, etc.)
- Other, please specify:

23. What was meaningful to you about this experience?

24. Do you think this program is worthwhile to expand across Washington State? Why or why not?

25. If you were given the task of redesigning the workshop, what would you change?

26. Do you have any final comments you would like to share with us?

**Thank you so much for your participation in the Dementia Friends Washington Program  
Evaluation!**

## 8.4 Dementia Champions' Pre-Training Survey



# Dementia Champions Pre-Training Survey

Thank you for participating in our evaluation of Dementia Friends Washington. Before attending the training to become a Dementia Friends Champion, we ask that you complete this survey. This survey takes about 20 minutes to complete and your responses are completely voluntary. You will also be asked to complete a survey after your training and again once you finish presenting all of your informational sessions. Once all surveys are completed, we will be giving each Champion \$20 gift cards as a small thank you for your time and commitment to this project. We are very grateful to have you be a part of our team! We look forward to seeing you in January and February at our training!

**To maintain privacy, your contact information will be stored separately from the rest of the questionnaire. We are asking for your contact information for our internal use only. We will not be sharing this information with others. We would like to contact you at the completion of the project to solicit your input and send you final results of our project at the end of 2019. Please let us know if you have any concerns or questions.**

If you have any questions or need assistance completing this survey, please contact Master Champion, Alisa Tirado Strayer, at [dementiafriendswa@gmail.com](mailto:dementiafriendswa@gmail.com).

**Name:** [Click here to enter text.](#)

**Address:** [Click here to enter text.](#)

**Phone Number:** [Click here to enter text.](#)

**Primary Email Address:** [Click here to enter text.](#)

**We would like to ask you a bit about your thoughts about dementia.**

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

	<i>Statements</i>	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Slightly Disagree</i>	<i>Neutral</i>	<i>Slightly Agree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1.	It is rewarding to work with people who have ADRD.	1	2	3	4	5	6	7
2.	I am afraid of people with ADRD.	1	2	3	4	5	6	7
3.	People with ADRD can be creative.	1	2	3	4	5	6	7
4.	I feel confident around people with ADRD.	1	2	3	4	5	6	7
5.	I am comfortable touching people with ADRD.	1	2	3	4	5	6	7
6.	I feel uncomfortable being around people with ADRD.	1	2	3	4	5	6	7
7.	Every person with ADRD has different needs.	1	2	3	4	5	6	7
8.	I am not very familiar with ADRD.	1	2	3	4	5	6	7
9.	I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
10.	People with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
11.	It is important to know the past history of people with ADRD.	1	2	3	4	5	6	7
12.	It is possible to enjoy interacting with people with ADRD.	1	2	3	4	5	6	7
13.	I feel relaxed around people with ADRD.	1	2	3	4	5	6	7

14.	People with ADRD can enjoy life.	1	2	3	4	5	6	7
15.	People with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
16.	I feel frustrated because I do not know how to help people with ADRD.	1	2	3	4	5	6	7
17.	I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
18.	I admire the coping skills of people with ADRD.	1	2	3	4	5	6	7
19.	We can do a lot now to improve the lives of people with ADRD.	1	2	3	4	5	6	7
20.	Difficult behaviors may be a form of communication for people with ADRD.	1	2	3	4	5	6	7

**We would like to ask about your knowledge of dementia.**

*Please check the box for the answer that you think is correct.*

	<i>Statements</i>	<i>False</i>	<i>Probably false</i>	<i>Probably true</i>	<i>True</i>	<i>I don't know</i>
1	Dementia is a normal part of the ageing process.					
2	Alzheimer's disease is the most common form of dementia.					
3	People can recover from the most common forms of dementia.					
4	Dementia does not result from physical changes in the brain.					
5	Planning for end of life care is generally not necessary following a diagnosis of dementia.					
6	Blood vessel disease (vascular dementia) is the most common form of dementia.					

7	Most forms of dementia do not generally shorten a person's life.					
8	Having high blood pressure increases a person's risk of developing dementia.					
9	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia.					
10	Symptoms of depression can be mistaken for symptoms of dementia.					
11	Exercise is generally beneficial for people experiencing dementia.					
12	Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition.					
13	The sudden onset of cognitive problems is characteristic of common forms of dementia.					
14	It is impossible to communicate with a person who has advanced dementia.					
15	A person experiencing advanced dementia will not generally respond to changes in their physical environment.					
16	It is important to correct a person with dementia when they are confused.					
17	People experiencing advanced dementia often communicate through body language.					
18	Uncharacteristic behaviors in a person experiencing dementia are generally a response to unmet needs.					
19	Medications are the most effective way of treating behavioral symptoms of dementia.					
20	People experiencing dementia do not generally have problems making decisions.					
21	Movement is generally affected in the later stages of dementia.					
22	People with advanced dementia may have difficulty speaking.					

<b>23</b>	People experiencing dementia often have difficulty learning new skills.					
<b>24</b>	Difficulty eating and drinking generally occurs in the later stages of dementia.					
<b>25</b>	Daily care for a person with advanced dementia is effective when it focuses on providing comfort.					

**Finally, we would like to ask some questions about you.**

1. What experience do you have with persons with dementia? [check all that apply]
  - I am a person with dementia
  - I provide care for a loved one with dementia
  - I provided care for a loved one with dementia in the past
  - I work with persons with dementia
  - I have family, friends or acquaintances with dementia
  - I have no prior connection to persons with dementia
  - Other:
  
2. Please list the names of any groups or networks that you are connected (i.e. service club, religious institution, sports team, work or volunteer organization, cultural group, neighborhood association, school, book group). These might be people or places to share your Dementia Friends presentation!
  
3. What is your employment status? [check all that apply]
  - Retired
  - Not currently employed
  - Student
  - Work full-time (30 or more paid hours a week)
  - Work part-time (less than 30 paid hours a week)
  - Other:
  
4. What year were you born?  
\_\_\_\_\_
  
5. What is your zip code?  
\_\_\_\_\_
  
6. Which of the following would you use to describe yourself? [check all that apply]
  - White
  - Hispanic or Latino(a)
  - Black or African American
  - Asian or Asian American
  - Native Hawaiian/ Pacific Islander
  - American Indian, Alaskan Native
  - Not listed above (please specify) \_\_\_\_\_
  
7. Which of the following best represents your current gender? [check only one]
  - Woman
  - Man

- Gender queer or non-binary or gender expansive
- Not listed above (please specify) \_\_\_\_\_

8. What is the highest level of education you have completed? [check only one]

- Less than high school
- High school or GED
- Less than 4 years of college
- 4 year college degree
- More than 4 years of college (master's degree or higher)

9. We would welcome any additional comments!

## 8.5 Dementia Champions' Post-Training Survey



# Dementia Champions Post-Training Survey

Thank you for attending the Dementia Friends Training today! We ask that you complete this survey now that you have been trained as a Dementia Friends CHAMPION! This survey takes about 10 minutes to complete and your responses are completely voluntary. We will be reaching out again in May to ask for you to complete a final survey once you finish presenting all of your informational sessions. Again, once all surveys are completed, we will be giving each Champion \$20 gift cards as a small thank you for your time and commitment to this project. We are very grateful to have you on this team!

**To maintain privacy, your contact information will be stored separately from the rest of the questionnaire. We are asking for your contact information for our internal use only. We will not be sharing this information with others. We would like to contact you at the completion of the project to solicit your input and send you final results of our project at the end of 2019. Please let us know if you have any concerns or questions.**

If you have any questions or need assistance completing this survey, come talk to your Master Champion, Alisa Tirado Strayer, or email her at [dementiafriendswa@gmail.com](mailto:dementiafriendswa@gmail.com).

**Name:** [Click here to enter text.](#)

**We would like to ask you a bit about your thoughts about dementia.**

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

	<i>Statements</i>	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Slightly Disagree</i>	<i>Neutral</i>	<i>Slightly Agree</i>	<i>Agree</i>	<i>Strongly Agree</i>

1.	It is rewarding to work with people who have ADRD.	1	2	3	4	5	6	7
2.	I am afraid of people with ADRD.	1	2	3	4	5	6	7
3.	People with ADRD can be creative.	1	2	3	4	5	6	7
4.	I feel confident around people with ADRD.	1	2	3	4	5	6	7
5.	I am comfortable touching people with ADRD.	1	2	3	4	5	6	7
6.	I feel uncomfortable being around people with ADRD.	1	2	3	4	5	6	7
7.	Every person with ADRD has different needs.	1	2	3	4	5	6	7
8.	I am not very familiar with ADRD.	1	2	3	4	5	6	7
9.	I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
10.	People with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
11.	It is important to know the past history of people with ADRD.	1	2	3	4	5	6	7
12.	It is possible to enjoy interacting with people with ADRD.	1	2	3	4	5	6	7
13.	I feel relaxed around people with ADRD.	1	2	3	4	5	6	7
14.	People with ADRD can enjoy life.	1	2	3	4	5	6	7

15.	People with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
16.	I feel frustrated because I do not know how to help people with ADRD.	1	2	3	4	5	6	7
17.	I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
18.	I admire the coping skills of people with ADRD.	1	2	3	4	5	6	7
19.	We can do a lot now to improve the lives of people with ADRD.	1	2	3	4	5	6	7
20.	Difficult behaviors may be a form of communication for people with ADRD.	1	2	3	4	5	6	7

**We would like to hear about your experience in this training.**

1. What did you learn in this training? (check all that apply)
  - I learned new information about dementia
  - I learned about giving a training
  - I learned more techniques for engaging with people with dementia
  - I was already familiar with the material presented
  - Other (please specify)
  
2. How engaging was the presenter?
  - Not engaging
  - Engaging
  - Very Engaging
  
3. How well do you feel about **recruiting for** your own Dementia Friends informational session?
  - Excellent
  - Good
  - Fair
  - Poor
  
4. How well do you feel about **presenting** during your own Dementia Friends Informational session?
  - Excellent
  - Good
  - Fair
  - Poor
  
5. How do you feel this information will be received by your recruited Dementia Friends?
  - Excellent
  - Good
  - Fair
  - Poor
  
6. We welcome any additional feedback about the training!

## 8.6 Dementia Champions' Interview Guide

*Thank you for everything you have done for Dementia Friends and for making time for this interview. The purpose of making this time to debrief your experience is to learn more about your experience in the Dementia Friends program. Since this was the first time we've done this program here in Washington, we know that there is certainly room for growth and are hoping to learn from what went well and what could go better. We anticipate this interview will take about 30 minutes.*

**1) Do you have any questions before we get started?**

**2) What were 2-3 reasons you first wanted to sign up to be a Dementia Champion?**

**3) Is there any information you wish you would have had BEFORE starting the program?**

**3a)** After you signed up, you attended a 3-hour training where you learned about the program, did some role playing, and practiced a script of the program with others. The purpose of that training was to expose everyone to the program and help everyone feel prepared to give their own talk. As we consider ways to improve the program, we would like to know how well that worked. **In general, how prepared did you feel to go out and offer a Dementia Friends program?**

**3b) How prepared did you feel to go out and locate a venue to offer a Dementia Friends program?**

**3c. How prepared did you feel to go out and to recruit people to attend the Dementia Friends program?**

**3d. What would have helped you feel more prepared?**

**4a)** After the training, you went out to give your own sessions. The model of Dementia Friends is meant to give a lot of autonomy for Champions to plan, advertise, find a venue, and give a training. That can be a lot for anyone and is a significant responsibility. We're curious how that worked for you. **How did you go about finding a location to hold the session? (find out where held, how recruited people)**

**4b) What approaches did you use to find people to attend? Which ones worked? Not work?**

**4c) What parts of putting together the session worked smoothly?**

**4d) What challenges did you experience organizing the session?**

**5a) While you were planning your session, we continued to reach out periodically through emails or calls and there was an email chain for the Champions to use to communicate with each other. What, if any, support was useful?**

**5b) What, if any, support was NOT useful?**

**5c) Is there anything that would have improved your experience or made you feel more equipped in your role to be successful?**

**6) Our intent in piloting Dementia Friends was to change people's attitudes towards dementia and to challenge stigma. How effective do you think this program was at changing attitudes about dementia?**

**7a) Our goal was to make sure the information was reaching people who don't often get information about dementia such as African American, Latino, and rural communities. Were you trying to reach any particular group with your training? If yes, what group?**

**7b) How do you think it went?**

**7c) How could the process be improved to better serve that group?**

**8) Now the pilot is finishing and we are not asking you to do anything more now, but we're curious to hear your thoughts on the program as it would normally be given. Usually the program only involved doing a couple sessions a year, instead of a couple in a few months. Could you imagine yourself feeling interested or motivated to give a couple of sessions a year in an ongoing way? Why or why not?**

**9) Once we analyze the data, if this program is found to be effective and we can find resources to support it, would you be interested in being contacted about future opportunities?**

**10) Do you have any final thoughts or questions?**