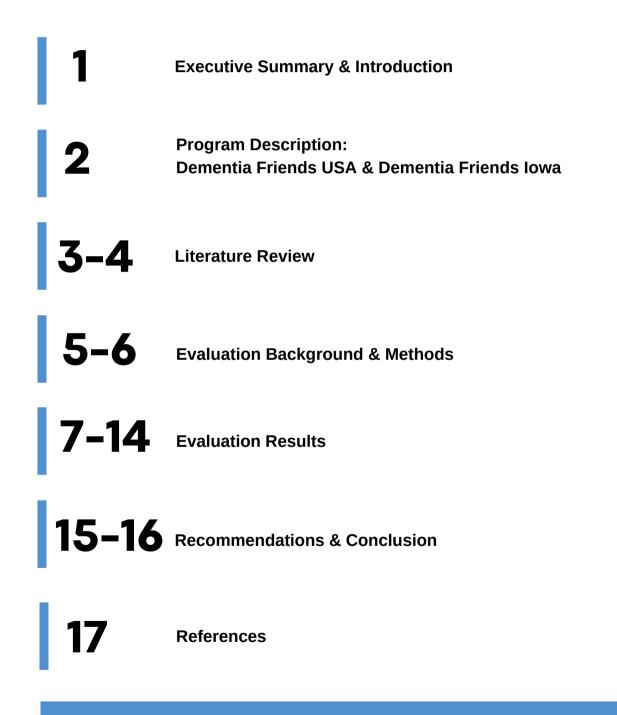
# Dementia Friends Iowa Evaluation Report

Megan Zimmerman, MS, LBSW and Dr. G. Joseph Sample





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MAY 2024

DEMENTIA FRIENDS IOWA EVALUATION REPORT

## July 2021 - December 2023 Dementia Friends Iowa Evaluation Report

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#### **Executive Summary**

The Dementia Friends Iowa program is a public awareness education program about dementia that focuses on increasing awareness and reducing stigma. The program launched July 2021 in Iowa through a partnership of Iowa's Area Agencies on Aging and other key stakeholder organizations. Evaluation efforts were implemented between July 2021 and December 2023 to better understand the effectiveness of the program in meeting its goals to: 1) enhance dementia knowledge, 2) increase social comfort, and 3) inspire action within communities. Data collected between July 2021 and December 2023 showed that over 8,000 individuals became Dementia Friends through 586 sessions that were held in 45 counties. Immediate post-session evaluations indicated that participants improved their understanding of dementia, enhanced their confidence in communicating with people living with dementia (PLWD), and increased participant willingness to support individuals living with dementia. Follow-up surveys conducted three months after participants completed the Dementia Friends session showed that participants continued to engage in dementia friendly actions inspired by the session. Feedback from participants emphasized the value of personal stories and videos in the sessions, indicating the importance of continued personal story and video usage for increased empathy and reduced stigma. Additionally, findings indicate a need to: 1) expand outreach to underserved populations, and 2) enhance future evaluation efforts to establish evidence-based outcomes. The evaluation indicates that the Dementia Friends Iowa program has been effective in fostering a greater understanding of dementia and inspiring participants to take action to support individuals living with dementia in their communities.

#### Introduction

Dementia Friends Iowa is a program of Iowa's Area Agencies on Aging with statewide coordination provided by the Northeast Iowa Area Agency on Aging (NEI3A), with partial funding from the University of Iowa Geriatric Workforce Enhancement Program. The Iowa Association of Area Agencies on Aging secured a Dementia Friends sublicense to conduct information sessions in Iowa from Dementia Friends USA in 2021. The goals of the Dementia Friends Iowa include increasing dementia knowledge, improving social comfort, and inspiring participants to take dementia friendly action in their communities. The program offers one-hour Dementia Friends sessions to the public which cover basics of dementia, communication tips, and recommendations to support fellow community members living with dementia. Anyone who attends a session becomes considered a "Dementia Friend" and is encouraged to choose a dementia friendly action to take in their community. The intent of this report is to provide key insights from the program evaluation data collected between July 2021 and December 2023, while also providing recommendations to strengthen the program and enhance future evaluation efforts.

#### Program Description: Dementia Friends USA & Dementia Friends Iowa

Dementia Friends USA is a dementia education program with the goals of raising public awareness of dementia, improving attitudes towards PLWD, decreasing stigma surrounding dementia, and inspiring community members to take a dementia friendly action in their community (Dementia Friends USA, 2022). The program is a one-hour session which covers basics of dementia, communication tips, and recommendations to support fellow community members living with dementia. Anyone who attends a session becomes considered a "Dementia Friend." The content of the program is built around the Five Key Messages of Dementia Friends which includes:

- 1. Dementia is not a normal part of aging.
- 2. Dementia is caused by diseases of the brain.
- 3. Dementia is not just about having memory problems.
- 4. It is possible to have a good quality of life with dementia.
- 5. There's more to the person than the dementia; people with dementia are a valuable part of the community.

The Dementia Friends USA program is a part of the greater Dementia Friendly America initiative, which is administered by USAging, a national advocacy organization for U.S. Area Agencies on Aging (AAAs) and Older Americans Act Title VI tribal organizations. The program has trained over 160,000 Dementia Friends across the country (Dementia Friends USA, 2022). The structure of the Dementia Friends USA program is a train-the-trainer model whereas each individual state with an active sub-license has a Champion Trainer who trains lay volunteers as "Dementia Friend Champions." These volunteers present Dementia Friends sessions to anyone in their community (Tirado-Rafferty, 2023).



The Dementia Friends state sub-license in Iowa was secured in 2020 by the Iowa Association of Area Agencies on Aging (i4a) (Iowa Association of Area Agencies on Aging, 2020). This launch included funding and a partnership between i4a, the Northeast Iowa Area Agency on Aging (NEI3A), and the University of Iowa Geriatric Workforce Enhancement Program (Iowa GWEP). The partnership and funding allowed for the development of a Dementia Friendly State Coordinator position to serve as the Champion Trainer for the Dementia Friends Iowa sublicense (held by i4a), and the Dementia Friendly Community state lead (held by NEI3A). The collaborative effort officially launched July 1, 2021 when the funding for the statewide coordinator position began (Northeast Iowa Area Agency on Aging, 2021). The goals of the Dementia Friends Iowa program are the same as the goals of Dementia Friends USA, which include increasing dementia knowledge, improving social comfort, and inspiring participants to take dementia friendly action in their communities.

The Dementia Friends Iowa program intends to provide Dementia Friends sessions throughout all 99 of Iowa's counties by ensuring Champion coverage throughout the state. By December 2023 (two and a half years post-launch), the Dementia Friends Iowa program had identified, trained, and retained 161 active Champion volunteers in 68 out of 99 counties, according to the self-reporting of Champions' preferred coverage areas.

In addition Dementia Friends Iowa had partnered with 59 various organizations across the state as "Supporting Organizations of Dementia Friends Champions," including all six Iowa AAAs, several retirement communities, universities, various non-profits, and more. "Supporting Organizations of Dementia Friends Champions" are organizations that have a minimum of one employee trained as a Champion and agree to support the efforts of the Champion by signing a memorandum of understanding. Champions are not required to be connected to a "Supporting Organization" (Dementia Friendly Iowa, 2023). Finally, 8,205 Dementia Friends had attended Dementia Friends information sessions across the state between July 2021 and December 2023.

#### **Literature Review**

Dementia is a rising public health concern across the world and in the United States. An estimated 50 million people are living with dementia worldwide (WHO, 2019). In the U.S, an estimated 6.7 million individuals are living with Alzheimer's disease, the most common type of dementia (Alzheimer's Association, 2023). The number of PLWD in the U.S. is expected to increase by at least 6.7% between 2020 and 2025 (Alzheimer's Association, 2023). In the state of Iowa, at least 63,000 individuals are living with dementia (Alzheimer's Association, 2023). Concerningly, there remains a large amount of stigma and misinformation surrounding dementia (Herrmann et al., 2018) that can contribute to social isolation for PLWD and their care partners (Tirado-Rafferty, 2023).



The negative stigma can impact how the person engages with their community and limits access to assistance, support, or a diagnosis (Alzheimer's Disease International. 2019). The implications of dementia stigma may negatively impact everyday interactions with others, family dynamics, and contribute to the exclusion of the voice of PLWD in their healthcare decisions or community involvement (Nguyen & Li, 2020). Stigmatizing dementia is often more prevalent in people with limited contact with PLWD or who lack knowledge of dementia (Herrmann et al., 2018).

Suggested effective interventions for reducing stigma include education about the topic to counter misconceptions about dementia, quality contact with PLWD, and challenging negative attitudes (Bacsu, 2022). Additionally, a recommendation to counter stigma from the World Alzheimer Report 2019 (Alzheimer's Disease International, 2019) included offering specialized education about dementia and dementia-related stigma to change negative perceptions of dementia. Advocacy for community-based initiatives relating to dementia education and awareness across the world have been implemented (Hebert & Scales, 2017). International dissemination of the Dementia Friends model is one such awareness and education model that has been a response for enhanced access to dementia information and education. Dementia Friends is a dementia education program with the goals of raising public awareness of dementia, improving attitudes towards PLWD, decreasing stigma surrounding dementia, and inspiring community members to take a dementia friendly action in their community (Dementia Friends USA, 2022). The Dementia Friends concept originally started in Japan, and has since been further developed in the U.K., catalyzing the spread of the program throughout several countries across the globe, including the United States (Alzheimer's Disease International. 2019).

Research on Dementia Friends programs have shown promising results. The Dementia Friends program was effective at increasing dementia knowledge in a sample of children in the U.K. (Farina et al, 2020), and was shown to improve attitudes towards and knowledge of dementia, and improved social comfort towards PLWD in a sample of college students (Cowan, 2021). Results showed that the program was effective at increasing knowledge of dementia, yet did not show statistical significance of an increase in social comfort or attitudes. In studies evaluating the effectiveness of improving attitudes towards dementia in college students in Minnesota, results showed improvement in both social comfort towards PLWD and knowledge of dementia Further, the Dementia Friends Program appeared to positively change attitudes, raise awareness, and inspire further engagement of a sample of nursing students at a U.K. university (Baillie et al., 2015). Additionally, the impact of Dementia Friends session material showed promising results in increased social comfort and knowledge, as well as a strong representation of dementia friendly post-session action steps chosen on other health professional students (e.g., pharmacy, medicine, physical therapy) (Berning et al., 2022). These favorable findings on the impact of the program has led one university to expand the Dementia Friends sessions throughout the university (Baillie et al., 2015).

The Dementia Friends program has also been useful outside of university settings. For example, the Dementia Friends program was administered and evaluated for staff of incarcerated settings. After attending the Dementia Friends session, the staff reported an increase in positive attitudes towards PLWD and reported increased confidence in personal interactions with PLWD, the ability to recognize behaviors due to dementia, and more positive outcomes in interactions between staff and PLWD (Bibbo & Nicolay, 2022).

Finally, a few evaluations have been implemented to gauge the effectiveness of statewide Dementia Friends programs. In Nevada, Carson et al (2020) evaluated the impact of the Dementia Friends program that offered sessions in several different communities, was open to the public, and presented to attendees of diverse backgrounds. Results showed a significant increase in dementia knowledge and strong response rate of committing to a dementia friendly action in their community. In Washington, a similar study was conducted to evaluate the impact of several Dementia Friends sessions offered to a variety of attendees in public settings. Tirado-Rafferty et al. (2023) concluded that "Dementia Friends sessions were effective in improving participant attitudes towards PLWD and inspiring ongoing action towards building Dementia-Friendly communities" (p. 2).

The findings of these studies point toward the effectiveness of Dementia Friends sessions at improving attitudes towards PLWD, increasing knowledge of session participants, and inspiring dementia friendly action steps following sessions by the participants. Despite these positive findings, there are limitations present in the current literature and in past evaluation data. First, many of the studies lacked a randomized control trial, which resulted in no control group to which outcomes could be compared. Another limitation in past research is that Dementia Friends USA has significantly expanded the program into multiple states (Dementia Friends USA, 2022), thus findings present a limited understanding of session outcomes on a broader scale. Finally, much of the past research has included a specific population of attendees at the sessions (e.g. college students, nursing students, staff of incarcerated settings) or a specific state.

On a larger scale, little to no research has been done to evaluate the effectiveness of the Dementia Friends program as a whole in

consideration of the significant growth of the program throughout the U.S. Continued evaluation of the Dementia Friends USA program would be significant and necessary to advance the credibility of the program's effectiveness of increasing knowledge, improving social comfort, and inspiring dementia friendly action for attendees. An impact evaluation could lead to a more widespread implementation and future funding for state programs.

#### **Evaluation Background & Methods**

The Dementia Friends USA program has not been mandated for state sub-licensees. Additionally, the implementation and types of evaluation differ by state. However, the Dementia Friends Iowa program began its own implementation of evaluation efforts in July 2021 in collaboration with Iowa GWEP. The following questions were utilized to evaluate the effectiveness and impact of the program:

- Does the Dementia Friends Iowa program increase participants' knowledge of dementia?
- Does the Dementia Friends Iowa program increase participants' social comfort towards people living with dementia?
- Does the Dementia Friends Iowa program inspire participants to implement a dementia friendly action in their community?
- Do the participants of the program follow through with taking a dementia friendly action in 3-months following the session?
- What type of dementia friendly actions do these participants choose to take? 6. What feedback do the participants have to improve the program?

These questions for the impact evaluation research are necessary to show if the Dementia Friends Iowa is effective in its goals of increasing knowledge, increasing social comfort, and inspiring participants to take dementia friendly actions in their communities. In addition, the evaluation questions allow for participants to give



valuable feedback for continued improvement of the Dementia Friends Iowa program.

The Dementia Friends evaluation began in July 2021 and has continued as the program has grown. For the purposes of this report, the evaluation data reported is from July 2021 through December 2023. The data collection method at its core involved all Champion volunteers self-reporting their sessions after presenting on an online form. The self-report included questions about the session location, number of attendees, and any notable feedback from the session. This report was automatically collected in a spreadsheet by the statewide coordinator.

The Dementia Friends Iowa evaluation plan also included a post-session survey distributed immediately at the end of any Dementia Friends session offered. Given the varying difference between Dementia Friends session participants, the survey was developed with consideration towards accessibility and versatility. Therefore, an identical paper evaluation form and an online evaluation form were created. Most in-person sessions utilized the paper evaluation forms, with the additional option of scanning a QR code to utilize the online evaluation form instead. The QR code was mostly used in cases where the Champion did not print out evaluation forms beforehand. For virtual sessions,

the link to the online evaluation form was provided in the meeting chat and/or distributed in an email to participants after the session. All Champion volunteers were instructed to allow time during the end of every session to distribute and collect evaluations, however, participants were not required to complete the evaluation form. All evaluation forms (both paper copy and online form) were returned to the statewide coordinator following the session.

The immediate post-session evaluation survey consisted of all optional fields, including name, email address (to be added to the newsletter), zip code, and demographic information. In addition, the survey included four questions to evaluate change in knowledge, social comfort, and inspiration to take a dementia friendly action step. These questions were rated on a five-point Likert scale. Finally, the immediate post-session evaluation concluded with two open-ended questions. One open-ended question prompted participants to share any feedback about the program, and the other open-ended question prompted participants to share any dementia friendly actions they hope to take in response to the session (see Appendix A for post-session evaluation form). Originally, the immediate postsession evaluation also included two additional open-ended questions to evaluate change in empathy for participants. However, these two questions were eliminated from the form in June 2022 in an effort to shorten the evaluation for participants. This evaluation report does not include results from these eliminated questions.

In addition to the immediate post-session survey, the evaluation plan also included a 3month follow up survey to evaluate if the participants' chose to follow through with taking dementia friendly action within 3-months after becoming a Dementia Friend. This follow-up evaluation was not developed and implemented until October 2022. This survey was distributed monthly to participants who initially provided an email address on their immediate post-session evaluation form. The 3-month follow up survey was distributed through an automated Constant Contact email, which included a link to the survey. The 3-month follow up survey included three questions. The first was closed-ended to identify if the participant had utilized information from the session in their personal or professional lives. The second question included a list of options to mark for the type of actions taken. The last question was open-ended, asking participants to share a story of how they have taken a dementia friendly action since the session (See Appendix B for 3-month Follow-Up Survey).

Between the three main parts of the evaluation process (Champion session reports, immediate post-session survey, and the 3-month follow up survey), the evaluation plan was developed to show if the Dementia Friends Iowa is effective in its goals of increasing knowledge, increasing social comfort, and inspiring participants to take dementia friendly actions in their communities. In addition, the evaluation questions allowed for participants to give valuable feedback for continued improvement of the Dementia Friends Iowa program.



#### **Evaluation Results**

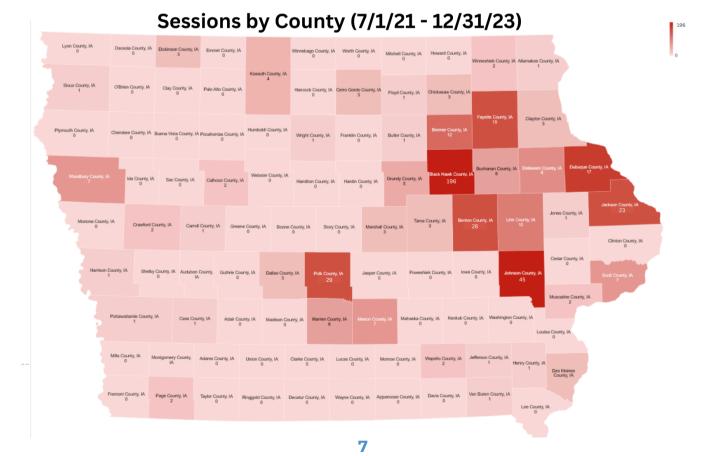
From July 2021 to December 2023, the Dementia Friends Iowa program had trained 161 active Champion volunteers in 68 out of 99 counties, according to the self-reporting of Champions. The statewide coordinator presented 28 Champion volunteer trainings. From July 2021 to December 2023, 586 sessions were presented by Champions. In those sessions, 8,025 people became a Dementia Friend. The sessions were offered to a variety of locations and groups of people. Groups included university students, youth groups, businesses, healthcare settings, family caregivers, civic groups, local government, non-profit organizations, and more. Overall, the sessions were offered in 45 counties across lowa, with the most concentrated number of sessions in Black Hawk County, which totaled 198 sessions (see Figure 1).

#### **Demographics**

Participants completed an immediate postsession evaluation (n=4,916). The demographics section of the evaluation provided insight into the individuals reached by the program, and results showed a wide variety of participants (see Figure 2). Perhaps the most demographic diversity was the ages of participants. All ages were welcome to the sessions, with the 20-29 and 60+ age ranges making up the majority (59%) of participants. Many of the session participants were practitioners or providers (including professional caregivers), with the next most common participants being students and family caregivers.

For gender, the participants were 76.3% female (n=3,387), 23% male (n=1,016), and .3% non-binary (n=17). The participants' race consisted of a majority white individuals (87%) (n=4,051), with black individuals the second most common (4.7%) (n=212). In addition, 2.1% of

#### FIGURE 1 Map of Sessions by County



participants reported Asian (n=93), 1.7% reported American Indian or Alaskan Native (n=75), and .5% reported Hawaiian or Pacific Islander (n=22). For ethnicity, 3.2% of participants reported being Hispanic or Latino (n=143).

Finally, the demographic section of the evaluation collected information regarding participants' backgrounds. Many of the participants (60.1%) reported growing up or currently living in a rural area (n=2,988). Additionally, 9.6% of participants described themselves as being from an economically or educationally disadvantaged background (n=472).

#### FIGURE 2

#### **Participant Demographics (n=4,916)**

Age	Percentage
19 & Under	16.1%
20-29	26%
30-39	11.1%
40-49	10.8%
50-59	12.4%
60+	33.5%
Community Role	Percentage
Faculty	0.2%
Student	16.7%
Family Caregiver	16.2%
Practitioner/Provider	66.8%
Gender	Percentage
Female	76.3%
Male	23%
Non-Binary	0.3%
Race	Percentage
White	87%
Black	4.7%
Asian	2.1%
American Indian/Alaskan Native	e 1.7%
Hawaiian or Pacific Islander	0.5%
Ethnicity: Hispanic	3.2%
Background	Percentage
Grew up or live in rural area	a 76.3%
Economically or educational disadvantaged background	

#### **Dementia Knowledge & Social Comfort**

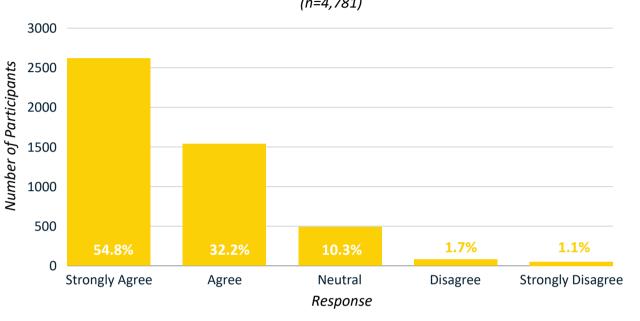
The immediate post-evaluation survey evaluated change in dementia knowledge and social comfort through two Likert scale questions. The majority of participants (87%) reported their awareness had increased about Alzheimer's and other related dementias (n=4,157) immediately after the session, indicating an increase in dementia knowledge (see Figure 3). Similarly, 85.7% of participants reported they now know how to communicate with a person with dementia (n=4,098) (see Figure 4).

#### **Dementia Friendly Action**

The immediate post-session evaluation survey also evaluated the participants' inspiration and commitment to taking dementia friendly action following the session. When asked if the participant is inspired to offer support and be a friend to PLWD in their community, 90.4% reported they strongly agreed or agreed (n=4,322) (see Figure 5). In addition, when asked if they are likely to adopt dementia friendly practices in their personal or professional lives, 92% strongly agreed or agreed (n=3,899) (see Figure 6).

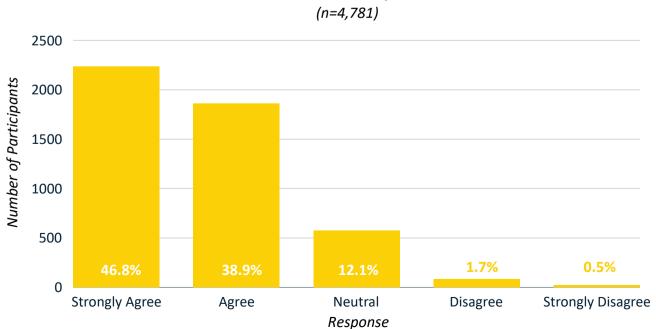


#### **FIGURE 3 Change in Dementia Knowledge**



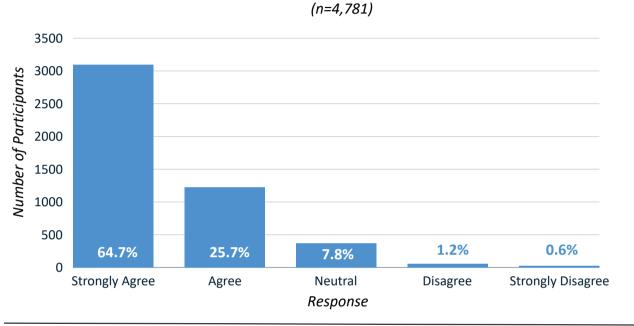
#### My awareness has increased about Alzheimer's and other related dementias. (n=4,781)

#### **FIGURE 4 Change in Communication Confidence**



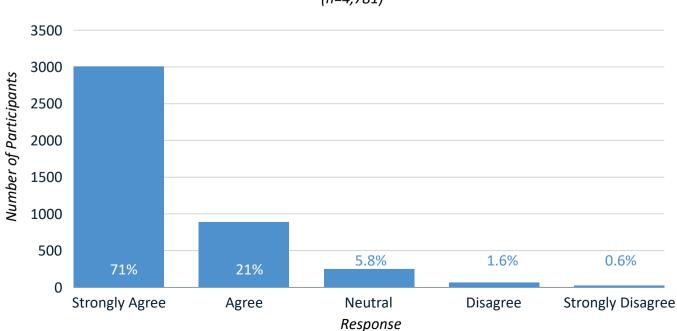
I know how to communicate with a person with dementia.

#### FIGURE 5 Post-Session Inspiration to Offer Support



I am inspired to offer support and be a friend to people living with dementia in my community.

#### FIGURE 6 Adoption of Dementia Friendly Practices



I am likely to adopt dementia friendly practices in my personal or professional life (n=4,781)

In addition to these two questions, the immediate post-session evaluation also allowed for participants to share if there was anything they hoped to do or change in response to this session to support PLWD. This guestion was open-ended, allowing for participants to share their plans for taking a dementia friendly action, if chosen. Overall, many participants shared actions they hoped to take, with most of the actions being helping someone when needed in the community, being more patient or aware in public settings, or changing the way they communicate with PLWD. One participant shared, "The way in which I approach/interact with those with dementia is forever changed!" Another commented, "I'll definitely take more notice of those around me in public and feel more empowered to approach someone who might need help." In addition, some participants alluded to changing language surrounding dementia to avoid contributing to the negative stigma. One participant shared, "I will modify my language used to describe those with dementia. Previously I have called the person demented, which I will no longer use, and I am going to change my idea

to a person LIVING WITH dementia and not suffering/dying from dementia."

In addition to these public-facing actions, several other respondents mentioned plans to reach out to keep in touch with someone in particular who they know living with dementia or utilize communication techniques learned in the session with a friend or family member. One participant highlighted this by sharing intentions to "call my grandmother more now that I am better equipped to interact with her." Another participant commented, "My father has recently been diagnosed and this has helped me understand it all much more clearly and given me tools to use. I am his primary caretaker and this has given me a place to start."

The most common themes in the comments for dementia friendly actions chosen included "help" (n=310), "patience" (n=302), "aware" (n=221), "community" (n=161), and "understanding" (n=147). These common themes can be seen in the word cloud, which include all words which occurred at least 20 times throughout the comments (see Figure 7).

#### **FIGURE 7**



#### **Post-Evaluation Actions Word Cloud**

In addition to the immediate post-session evaluation, the dementia friendly actions chosen by participants were also collected through the 3month follow up survey. Overall, 269 participants responded to the three-month follow up survey. Of these participants, 92.2% (n=248) shared they had used information from the training in their personal or professional life since the Dementia Friends session. In addition, the survey asked participants to indicate which type of dementia friendly action they had taken since the session three-months prior. The most common action taken was that participants had shared the information learned with someone who might benefit, which accounted for 22.9% of participants (n=166). One participant in particular reported, "I shared this program idea with my employer because we serve older customers. I am happy to say they will offer it to our staff!" Other participants shared the information in more informal settings; one participant reported, "I shared the information with the ladies in my exercise group. They appreciated it." Finally another participant shared. "I have shared information about Dementia Friends with several of my friends and family members, encouraging them to watch for people in their neighborhood and in their lives to see if there's a way they could help."

In the 3-month follow-up survey, 22.7% of participants shared they had carried out a personal action (such as being more patient when out in the community) (n=164). Some participants' personal actions were taken with family members living with dementia. One participant stated, "My spouse has early onset dementia and I learned things that help me as her caregiver." Similarly, another participant shared, "I learned new ways to better care for our mother. Things I learned at the seminar made living with someone having dementia a bit easier." Finally, some personal actions were taken in more public settings. One participant reported, "I had a lady living with dementia attend a Bible



study I led a few times. The first time she attended I had not yet attended the Dementia Friends session. I did not understand her behavior or how I should respond, so I did not interact with her very much and allowed the individuals she came with do most of the interacting with her. I then attended the Dementia Friends session and was able to successfully include her more the next few times she attended."

The third most common action included changing language about dementia (such as "living with dementia" instead of "suffering with dementia") (15%) (n=109). Participants reported being more aware of how they speak about dementia. One participant shared, "I have been very careful to use the correct way to speak of dementia, and how to speak positively with someone with dementia." Another participant changed her own language on dementia and encouraged others to do the same. She reported, "I have spread awareness/language changes to other college students so they can be more insightful within their particular fields."

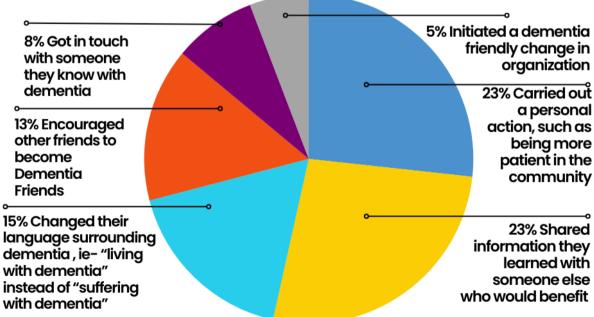
Finally, 12.4% (n=90) of participants encouraged friends to become Dementia Friends, and 8% (n=58) got in touch with someone they know who is living with dementia (see Figure 8). Some participants reported visiting or calling their loved ones with dementia more often. One participant stated, "I have been calling my grandma more often and being more patient with her...learning more about dementia at Dementia Friends helped me to be more considerate when talking with her, and also less scared to talk to her." In addition, another participant visited her aunt with a better understanding of how to interact with her. She shared. "I have an aunt with dementia. She did not know me when I visited, but connected with my sister. In recognizing me for just a short time, I did not feel any sadness about the visit. I'm happy I attended the session as I knew what to expect with my aunt suffering from dementia."

Another 17.9% (n=130) of participants shared they carried out a different action, such as

contacting a community resource, volunteering for a dementia-related organization, becoming a Dementia Friends Champion volunteer, or something else. Finally, 1% (n=7) shared they had not yet taken action. Participants were also invited to share a story of how they had used the information in the past 3-months following the session.

#### **Program Feedback**

To collect valuable feedback for continued improvement of the program, the immediate post-session evaluation allowed for participants to share any feedback or suggestions in an openended answer. Overall, participants provided positive feedback about their experience, especially about the manner by which the information was presented. One participant shared, "This presentation was realistic, clear, and insightful." Yet another participant commented, "I am glad that the emphasis of this program uses awareness, patience, kindness, and positivity."



### FIGURE 8

**Three-Month Follow Up Outcomes** 

The comments also reflected that participants especially appreciated the content of the program, including the videos included in the session, specifically the video of a local person living with dementia, which was reflected by several comments about the video of first-hand experience was touching and inspiring. One participant commented, "This is the best training we have had yet. A lot of good, informative videos with real people was great to see." Another participant shared, "It was super helpful to hear from someone with dementia. Gave us a better understanding and greater perspective."

The most common themes in the comments included "informative" (n=320), "helpful" (n=260), "great" (n=260), "good" (n=208), and "learned" (n=173). The word cloud reflects all the words and phrases which occurred in the program feedback portion of the evaluation at least 25 times throughout the responses (see Figure 9). Participants' responses also included

#### mentions of their own personal experiences with dementia, such as with a parent or partner. Several of those comments included mention of wishing they had this information sooner as their loved one has now passed away. Finally, many of the participants expressed gratitude and appreciation for the session, noting that they learned or became more aware of dementia and its impact on their community.

#### **Evaluation Summary**

In conclusion, the evaluation results of the Dementia Friends Iowa program demonstrate its effectiveness in meeting the intended goals of increasing knowledge, social comfort, and inspiring dementia friendly actions among participants. Through the commitment of a dedicated team of Champion volunteers, the program has reached a diverse audience spanning a variety of geographic locations, demographics, and backgrounds. The impact of the program is highlighted through participants' increase in awareness of dementia and communication skills.

#### FIGURE 9

Post-Evaluation Feedback Word Cloud



Most importantly, participants' commitment to taking dementia friendly action in their community, not only immediately after the session but in the months following, is a testament to the longer lasting impact of the program. Dementia Friends have taken action within their own workplaces, families, friendships, greater communities, and other circles of influence. Overall, the Dementia Friends lowa program has proven to be a valuable initiative in promoting understanding, empathy, and impactful action towards PLWD and their communities.

#### **Recommendations**

A few key indicators of gaps and strengths of the Dementia Friends Iowa program became evident in the evaluation report. Several recommendations could be considered to improve programming and outcomes in the future. First, the Dementia Friends Iowa program should continue to capitalize on the strength of utilizing personal stories of dementia in the sessions. Personal stories shared by presenters and videos of lived experiences have proven to be powerful tools in increasing awareness and understanding of dementia within the Dementia Friends sessions, as several participants indicated in the surveys. The Dementia Friends Iowa program should continue to incorporate and highlight these elements to provide participants with real-life perspectives to foster increased empathy and decreased stigma.

Another recommendation for the future of the program is to strengthen and expand outreach to a variety of diverse and underserved populations. To ensure inclusivity and diversity, the program should more actively reach out to underrepresented demographics, including individuals from various gender, racial, and language backgrounds. In addition, the program should consider identifying more Champion volunteers in unreached areas, particularly in



rural counties in Western Iowa. This could be achieved through targeted advertising, partnerships with community organizations, and tailored outreach strategies. Expanding outreach to diverse populations will help ensure more equitable access to dementia education throughout the state.

In addition to programmatic recommendations, the evaluation findings also point towards further opportunity for evaluation. Based on this current evaluation data, the Dementia Friends program shows promising potential to eventually become recognized as an evidence-based program. To strengthen the program's credibility and funding opportunities, future evaluations should aim to establish evidence-based outcomes. For Dementia Friends to become recognized as evidence-based, both nationally and statewide, a more robust evaluation would be necessary. For example, incorporating validated instruments for measuring outcomes, such as the Dementia Attitudes Scale (O'Connor & McFadden, 2010), would enhance the reliability and validity of evaluation data. In addition, implementing a pre-session assessment paired with the post-session assessment would enable evaluators to see the true changes in participants' knowledge, attitude, and behaviors as a result of Dementia Friends session attendance. Finally, expanding cohesive

evaluation efforts across all states with an active Dementia Friends program would provide the opportunity to understand the effectiveness of the Dementia Friends USA program as a whole, rather than only individual state programs. As the Dementia Friends program continues to expand nationally, it is imperative to strengthen cohesive evaluation efforts to understand the impact of the program and have the potential to become recognized as an evidence-based program.

#### Conclusion

The evaluation of the Dementia Friends Iowa program highlights its effectiveness in enhancing knowledge, social comfort, and inspiring action within communities. Dementia Friends Iowa has implemented comprehensive evaluation efforts since July 2021. Data collected between July 2021 and December 2023 revealed significant outcomes with over 8,000 individuals becoming Dementia Friends through 586 sessions held in 45 counties. Immediate post-session evaluations showed improved understanding of dementia, enhanced confidence in communicating with PLWD, and increased willingness to support individuals living with dementia. Follow-up surveys three months later indicated sustained engagement and commitment, with the majority of participants implementing a variety of dementia friendly actions in their personal or professional lives. Feedback from participants emphasized the value of personal stories and videos in the sessions, showing the importance of their continued usage for increased empathy and reduced stigma. Other recommendations for the program include expanding outreach to underserved populations and enhancing evaluation efforts to establish evidence-based outcomes.

In summary, the Dementia Friends Iowa program has proven to be an effective initiative in fostering greater understanding and inspiring participants to take action to support individuals living with dementia. By capitalizing on its strengths, addressing gaps, and expanding future evaluation efforts, the program has the potential to make an even greater impact, pave the way for broader implementation in other states, and pursue recognition as an evidence-based program.





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## **Become a Dementia Friend!**

- If you are an Iowa resident, visit: <u>https://dementiafriendlyiowa.org/</u>
- If you live in another state, visit: <u>https://dementiafriendsusa.org/</u>



For electronic copy, use your phone's camera to scan QR code or visit <u>https://dementiafriendlyiowa.org/what-is-dementia-friends-iowa/</u>

For questions or comments, email mzimmerman@nei3a.org