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Creating a Culture Change: Sector Trainings for Dementia Friendly Communities for East Central Illinois Area Agency on Aging

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CREATING A CULTURE CHANGE: SECTOR TRAININGS FOR DEMENTIA FRIENDLY COMMUNITIES FOR EAST CENTRAL ILLINOIS AREA AGENCY ON AGING

by

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ABSTRACT

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Title: CREATING A CULTURE CHANGE: SECTOR TRAININGS ON DEMENTIA FRIENDLY COMMUNITIES FOR EAST CENTRAL ILLINOIS AREA AGENCY ON AGING

Institution: Illinois State University

Capstone Advisor: Dr. Livia Stone

Concentration: Master of Sciences in Anthropology

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Regarding dementia, the public usually does not have a clear understanding of what it is and what it entails. People use it interchangeably with Alzheimer’s, which is not the same; and people fear it as it is part of the aging process, which is understandable but not true. Both of these misconceptions and more can be countered by implementing a dementia-friendly community (DFC). DFCs are cities that bring together different sectors (banks, hospitals, libraries, etc.) to create a cohesive network of resources, with their employees trained to interact with and bring awareness to persons with dementia (PWDs). During my practicum at East Central Illinois Agency on Aging (ECIAAA), I created presentations called sector trainings that provided this information. Through this experience and dementia trainings provided, I connected what I learned on the field to my anthropology and community development classes.

Keywords: Stevenson Center, dementia, dementia friendly communities, persons with dementia, older adults, area agencies on aging, Alzheimer’s, community development, non-profit sector, gerontology

To the older adults, persons with dementia, and the caregivers in our communities

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Introduction: The Shelf

As an Applied Community and Economic (ACED) Fellow at Illinois State University (ISU), I believe that all experiences eventually lead to potential opportunities to help and serve others. One of my earliest memories related to the older adult community was visiting a nursing home when I was six or seven years old. I remembered the smell, sterile yet sour. I remembered the sights, yellowed and peeling walls. Weathered board games. Small, bright greeting cards. Most of all, I remembered the residents. And although they were not Filipino or even Asian, they reminded me of my grandmother, Lola Mamang.

Honestly, I forgot what exactly we were doing there. However, when I left the nursing home, I remembered realizing that families left their parents or grandparents in there. (Later I would add "to die" at the end of that thought.) Like a plaything, these older adults were shelved by their families, out of sight and out of mind. Until the family wanted to visit, at which point the residents were brought back out. Through my later life experiences, I know that this perspective was not completely warranted, especially with how dedicated many nursing home staff were to the residents and their families.

But, in my kid brain raised in a Filipino household, it was weird at worst, confusing at best. In Philippine culture, grandmothers (lolas) and grandfathers (lolos) typically lived in one of their children's homes, usually helping raise their grandchildren. In my family's case, our Lola Mamang lived with us and then with my Tito Ogi, who always lived fifteen minutes or less away from us. So, I was accustomed to seeing my Lola Mamang on a weekly basis, at minimum. My two younger sisters and I would visit, watching Tagalog game shows or dramas, eating whatever food she made us, and getting gifts like clothes when we would leave a couple of hours later.

In short, my child-self could not fathom why a family would leave their lolas and lolos in something like a nursing home. I grew up being extremely uncomfortable and very anxious about the thought of being near a nursing home. Even though I was very young when I made “the shelf” observation, this unintentionally stigma-based thought remained unchallenged until I volunteered with Mind&Melody during college, a non-profit that played music for people with dementia (PWDs). This mindset cracked and eventually crumbled when I started my graduate school professional practice at East Central Illinois Area Agency on Aging (ECIAAA).

The purpose of this capstone was to outline my journey in learning about Dementia-Friendly Communities (DFCs) and creating Sector Trainings for future locations in ECIAAA’s service area. In this capstone, I will go through my experiences before, during, and after learning about the basics of DFCs. First, I started with the foundations of older adult initiatives that were vital for me to learn in order to get a solid basis for DFCs: Older Americans Act, Area Agency on Aging history, and Reducing Social Isolation (RSI) initiatives.

Second, when it comes to learning about DFCs, I described the process of me becoming a Dementia Friend (DF), Dementia Champion, and Dementia Leader. Included in this process was the original plan for my capstone, which was to document the Toolkit process found on the Dementia Friends America website.

Finally, the Sector Trainings section was a culmination of all the knowledge listed in the previous section, with information added to tailor to a location or business. The Sector Trainings were used to educate “sectors” of a community (e.g., neighborhoods, banks, transportation, etc.) of how to best accommodate and assist someone when they see a person with dementia (shortened by some as PWDs). My capstone project consisted of creating a series of sector trainings used by future presenters representing ECIAAA. Although there were existing documents and presentations used as sector trainings, my coworker and ECIAAA's Community Liaison Sheila Greuel identified a need for a more condensed version for smaller trainings, like a Lunch and Learn. As the future presenter of these sector trainings, Sheila believed in the mantra "less is more" and felt that the shorter presentations I made would create a more impactful and memorable experience, rather than overwhelming the audience with text-heavy slides. As ECIAAA's Community Liaison, her input and opinions were vital because she would be the primary person hosting these sector training events. The contribution of my capstone project was important because the sector trainings were one of the foundations of creating a dementia-friendly community. This section also contained my community development coursework connection and anthropological reflection upon what I learned about DFCs and how to apply this knowledge to future endeavors outside of my graduate experience. In all, I wanted to showcase how my contributions to ECIAAA will help them grow, sharing the knowledge that others shared passed on to me in a cycle of learning from the community to create DFCs together. I hope that it will give you more insight into older adults with dementia that you may encounter in the future.

Methods Challenges: The Pandemic Disclaimer

One of the most important factors in anthropology is participant observation, the cultural immersion of learning about a community by being a part of it and being a part of the processes of their society. My 11-month contract with ECIAAA started on July 2020 and ended May 2021, right in the middle of the COVID-19 pandemic. Because of this global pandemic, I could not meet anyone in person to learn more about them while in their environment. Due to the strict policies of nursing home visitations, no one who was not a staff member or ombudsman, an older adult resident advocate, could get into the facilities. I could not attend any trainings in person to organically mingle with others in the older adult field. I had never even physically met the person I worked with the most outside of my supervisor. Due to these huge limitations, a major part of this capstone is lacking.

However, the pandemic limitations also led to some good. Going back to the topic of trainings, the longest session I attended was a month-long, weekly session with RUSH University Medical Center, located in Chicago, Illinois. Under normal circumstances, that training would require hours of traveling. By utilizing Zoom and making the opportunity more accessible, the event organizer Susan Frick said they tripled or even quadrupled the number of attendees since their previous training. Additionally, the pandemic's use of Zoom and other webinar platforms allowed for me to attend meetings back-to-back and to have a digital copy of the presentation beforehand, which some people were reluctant to release. This flexibility was good for time efficiency but not the best for healthy scheduling boundaries. Luckily, my meetings were not always back-to-back. Working on this pandemic presented unique challenges that would not normally be an issue, but it also gave new opportunities that would not have been possible without the pivots that organizations made for the pandemic.

<u>What is ECIAAA? The Stage, Act I</u>

What is ECIAAA? East Central Illinois Area Agency on Aging

For a mid-western community, Bloomington-Normal has many unexpected distinctions. On a local level, having ISU as a state university and IWU as a prominent private college brought in diverse amounts of people. On a national level, we have the most restaurants per capita and have State Farm headquarters in town. Between those two levels, East Central Illinois

Area Agency on Aging (ECIAAA) holds the distinction on a state level of having the largest number of counties under their jurisdiction.

To start, I will explain what the Older Americans Act is. Then, I will do the same regarding what an Area Agency on Aging is and its purpose. Next, I will talk about reducing social isolation (RSI) committees and Dementia Friendly Communities (DFCs). Finally, I will describe my role and my purpose in ECIAAA, which was to reduce social isolation among older adults in east central Illinois.

What is the Older American's Act? The Foundation of All (Area Agencies on Aging) AAAs

In order for me to understand what ECIAAA does, my supervisor and Executive Director Susan C. Real trained me on and guided me through the Older American's Act.

The Older American Act outlined their role as the:

> […] major vehicle for the organization and delivery of social and nutrition services to [older adults] and their caregivers. It authorize[d] a wide array of service programs through a national network of 56 state agencies on aging, 618 area agencies on aging, nearly 20,000 service providers, 281 Tribal organizations, and 1 Native Hawaiian organization representing 400 Tribes. The OAA also include[d] community service employment for low-income older Americans; training, research, and demonstration activities in the field of aging; and vulnerable elder rights protection activities. (Administration for Community Living 2021)

An Area Agency on Aging (AAA) is a non-profit that works together yet separately with government entities, such as the Department of Health and Human Services and Illinois Department of Aging. They collaborated on providing funding, assistance, and guidance to service providers geared towards older adults and all others that fall under the Older Americans Act.

Specifically, for ECIAAA stated that:

> The East Central Illinois Area Agency on Aging is a non-profit organization, founded in 1972, and authorized under the federal Older Americans Act and the Illinois Act on Aging to plan and administer services for older adults, persons with disabilities, caregivers, and grandparents.
>
> [ECIAAA's] mission [was] to empower older adults, persons with disabilities, caregivers, and grandparents to age strong and live long – to live in their homes with dignity and safety, manage chronic health conditions, participate in community-based programs, prevent unnecessary institutionalization, and make informed decisions.
> (ECIAAA, 2021a)

What is Reducing Social Isolation? My Purpose at ECIAAA

My role as the Stevenson Fellow and purpose within ECIAAA was primarily to help reduce social isolation among older adults. The main way I did so was assisting with the maintenance and upkeep of three Reducing Social Isolation (RSI) committees in McLean County, Macon County, and Champaign and Vermillion Counties. McLean County met monthly, Macon County met every two months, and Champaign and Vermillion Counties met quarterly. In these meetings, county members from different sectors collaborated with and updated one another on their involvement in the older adult community. Two out of the three committees had pilot projects, which were key initiatives in that county, supported through ECIAAA funding.

When it came to county members within the RSI committee, they came from different sectors of the community. For example, the RSI McLean Committee has members from an Activity and Recreation Center (ARC) for older adults, the Bloomington Housing Authority, two public libraries, two transportation assistance organizations, a CPoE / SIS partner called CCSI that help seniors find resources in the area, Illinois State University, and University of Illinois. The Committee recently added YWCA, Carle BroMenn, and the Alzheimer's Association. This list contained the medical sector that many expect to have when discussing the topic of older adults, but most of them did not join until over three-fourths through the duration of my professional practice. However, it also contained sectors that provide resources to seniors that we do not often think about.

For instance, both libraries catered to the Bloomington-Normal area. They had programming and media in addition to books for all ages. When it came to their older adult patrons, staff members were accustomed to seeing some on a weekly or even daily basis. Because of the COVID-19 pandemic, the libraries' staff had to be creative with their outreach to seniors. They either developed or upgraded programs that brought pop-up libraries or bookmobiles to nursing homes. The staff would bring a select number of books for seniors to check out, and they would come back later to retrieve the books and offer new ones. This type of approach was not typically seen as senior care, but it was, and it should be. Taking care of seniors only in a medical aspect, especially if because they were seen as the most vulnerable, discredited those whose issues were less visible but were still just as prominent.

This type of thinking, helping those who did not know that they needed help and were overlooked, was the foundation of what RSI Committees do. To clarify, this was not along the same vein as "white savior complex" or voluntourism. Helping those who did not know they needed help referred to seniors who were isolated and lonely, but they did not acknowledge or realize that they fell into these categories because they, for example, lived with their family or were around people in general. Not only did the committee meet to plan ways to promote RSI, but they also wanted to raise awareness that it was a prevalent issue. This was even more prominent because of the current COVID-19 pandemic. These meetings occurred on a routine basis, so that we maintained this vision of supporting older adults during this emotional and psychological hardship.

For each meeting, my supervisor and our Executive Director Susan C. Real would start it off by reading the purpose of the meetings:

> The purpose of the Reducing Social Isolation Committee [was] to bring together community leaders to share their ideas in how we [could] collaborate to supplement already existing services with creative ways to reduce social isolation among older adults in [insert county here] County. (ECIAAA 2021b, 1)

To her, it was important to repeat it at the beginning of each committee meeting because she wanted everyone to keep the mission on the forefront of their minds.

What is a Dementia-Friendly Community (DFC)? My Capstone Focus

To promote RSI initiatives in our 16-county area, my supervisor and Executive Director Susan C. Real proposed the idea of creating a Dementia Friendly Community (DFC) in one of our RSI committees. She hired a Community Liaison Consultant separate from ECIAAA named Sheila Greuel. I worked with her in learning about DFCs, sector trainings, and how to become a DFC through DFA (Dementia Friends America). According to Dementia Friends America, the leading organization in the United States for this initiative and the origin of the DFC designation, a DFC was:

> a village, town, city[,] or county that is informed, safe[,] and respectful of individuals with [dementia], their families and caregivers and provides supportive options that foster quality of life. (Dementia Friendly America 2021b)

To promote this vision of a DFC, the locality had to provide accommodations, education, and sustainability throughout all sectors within it. Sectors are different parts of a city that people living in it used or visited. Examples included neighbors and community members, local government, businesses, pharmacies, banks, spiritual communities, libraries, health care, legal sectors, community-based services and supports, residential and specialty care, hospitals, and transportation. Accommodations varied from physical structure changes, such as painting walls a different color and other examples mentioned in the sector trainings. Education involved sector trainings, which were presentations or documents distributed to different parties and stakeholders in the community. Examples included libraries, banks, hospitals, and other resource providers in the area. Sustainability was important because the initiative never ended as long as there were people to support and people to inform. With the capstone's focus on DFCs and sector trainings, the capstone product exemplified how to accommodate needs, educate people, and sustain progress through different parts of the city.

The theory behind and importance of DFCs was that culture changes in the community for PWDs were reasonable and possible, with the right amount of knowledge and strong leadership from sectors throughout the towns. DFCs brought the community together with a shared goal of making sure PWDs (persons with dementia) could live healthy and fulfilling lives, despite the stigma and other negatives surrounding the disorder. Most cities already accommodate the physical needs of people who are blind. The DFC initiative aimed to show that people with cognitive needs, such as PWDs, also benefited from physical changes in their environment and changes in behavior from others. Culture change was also what Reducing Social Isolation (RSI) committees wanted to create for older adults in general.

The difference between an RSI initiative and a DFC initiative was that the former was broader, and the latter was more specialized, with both ideally supported by an Area Agency on Aging (AAA). DFCs could fall into a type of initiative for an RSI, similar to Alzheimer's falling into the category of dementia but not the other way around. RSIs were important because they helped older adults in general with social isolation, while DFCs were important as a sub project under RSIs that assisted specifically PWDs. Although both DFCs and RSIs required the community to work together, DFCs formally reached out and needed as many sectors as possible. On the other hand, RSIs were laxer and were comfortable with people coming and going without a feeling of detrimental loss. For example, if the hospital sector left either initiative, RSIs could try supplementing with other forms of healthcare providers. With DFCs, the loss of the hospital sector would create a major challenge due to the lack of representation from such an integral part of dementia care. Depending on the initiatives, RSI committees usually met on a monthly, two month, or quarterly basis to keep each other updated. DFCs meetings ranged from biweekly to every two months, depending on what stage they were in for creating a DFC. Finally, RSI initiatives did not have an entity giving them some sort of formal authority, while DFC initiatives had Dementia Friends America (DFA) that certified their status as a DFC on a nation-wide scale. Having a DFC certification was important because it allowed the town to state that they were active and willing to help PWDs.

Dementia Friends America was the organization that certified a community as a DFC, the process involving a four-step plan: Convene, Engage, Analyze, and Act (Dementia Friendly America 2021a). When my assignment started, we predicted that I would help complete the first step, convening “key community leaders and members” to gauge interest and find leaders for making the project happen and sustaining it (2021a). Due to COVID-19 and the vaccination preparations for the older adult and health communities, DFCs could not proceed as far as we had previously planned.

<u>What is Dementia: The Stage, Act II</u>

What is Dementia? Professionally and Personally

Dementia is a cognitive disorder that affects memory to the point that someone cannot live independently, with or without accommodations (Alzheimer's Association 2021). Although it is commonly found among older adults, one of the biggest stereotypes that needs to be broken is the age in which dementia occurs. People as young as thirty could get dementia, as evident in the film *Too Soon to Forget*, created by RUSH University Medical Center, one of the leaders in dementia medical research and initiatives in the United States. Dementia also occurs on a spectrum, meaning that some people with dementia can live independently with some support. The diagnosis is not a death sentence, but it still has obstacles for everyone involved, from family to doctors to caregivers and care receivers.

When I was in college, I volunteered for a non-profit called Mind&Melody. Their mission at the time was geared towards older adults with neurological impairments, but their new mission is to "work with older adults with or without neurological impairments, active older adults, and kids with disabilities" (Mind&Melody 2021). Mind&Melody volunteers did this by visiting nursing homes and care facilities, teaching people with instruments, and playing music for them. As mentioned before, I did not like the concept of nursing homes, which was where most of the volunteer locations were. I was recovering from health problems and felt like it was time to volunteer with other organizations that I was unfamiliar with, since I was accustomed to working with the immigrant community. Between having friends in the non-profit and wanting to face my fears of nursing homes, I chose to volunteer with Mind&Melody.

Every week or two, about five to seven of us would drive or take an Uber to the designated nursing homes. Because of the wealth disparities in south Florida, the nursing homes we went to were either small and modest or spacious and modern. This was one of the reasons Mind&Melody charged for visits on a sliding scale, with smaller organizations receiving the same type of service as the bigger organizations but at a lower price. One of the reasons for the pricing was because not only were there volunteers like me that helped for free, but there were professional musicians contracted with Mind&Melody that were paid volunteers.

Tying back to the present, this experience related to the capstone two-fold: first, it gave me insight on how non-profits that work within the health sector, in particular those with older adults and/or persons with dementia, conducted themselves. This was personally important to me because I wanted to learn how other types of non-profits ran their organization since I intended to work in the non-profit sector as a career. Second, it helped me overcome part of the stigma that I held about nursing homes for one and a half decades. This set the stage for my ECIAAA experience to tear down my remaining biases with my work as I learned about older adults, persons with dementia (PWDs), and DFCs.

Preliminary Dementia Research

I was like many people in terms of language, interchangeably using Alzheimer's and dementia with one another. Before I learned more through my professional practice, I thought both described an older adult who had memory difficulties that declined over time at a more rapid pace than usual. Through this professional practice, I learned that not all people with dementia were older adults and that the loss of memory was not a typical part of the aging process (Frick 2020b). More importantly for this capstone, I learned that dementia and Alzheimer's were not the same. A series of educational videos about brain health by Trinity College compared dementia and Alzheimer's to shortness of breath and asthma (Trinity College Dublin 2014). Dementia and shortness of breath were symptoms, while Alzheimer's and asthma were the diagnosis. For example, shortness of breath could be because of an allergic reaction, a recent run, or an anxiety attack (2014). Shortness of breath did not always mean that someone had asthma. Likewise, dementia could lead to other diagnoses, such as Lewy-Body disease. Dementia did not always mean someone had Alzheimer's.

Many educational sources in the health field emphasized PWD's need for differing and distinct details in discrete physical environments. Two examples that stuck out to me were: 1) wall, floor, and door coloring and 2) unique and non-repeating spaces. More examples will be expanded upon in the Sector Training section. For the walls, floors, and doors coloring, experts recommended using different colors to indicate doors that they can use and the same colors to hide doors (Stoub 2020). In addition, the floor should not have random solid black or reflective coloring so that PWDs did not fear falling into a hole or slipping on water (Rothenberg 2020). For the unique and non-repeating spaces, experts recommend not living in a cookie-cutter apartment complex or neighborhood (2020). Distinct landmarks and diverse housing make it less likely that a PWD did not get lost or confused (2020). Changing the environment seemed daunting when discussed on the large scale of an apartment complex or neighborhood; however, within the realm of a sector's building, small adjustments such as colors made a huge difference for PWDs and their caretakers. Just like we have accommodations for physical disabilities, people and businesses are fully capable of making these minor changes in space to introduce lasting change in society.

<u>Introductory Dementia Trainings: The Immersion</u>

Dementia Friends Training

The Dementia Friends Training was the first step towards learning about dementia and DFCs. It consisted of a video talking about dementia, persons with dementia (PWDs), and advice related to the former two. The advice consisted of what is dementia (a disease affecting memory), how to identify a PWD (someone who seems lost or confused but cannot convey what they are lost or confused about), how to approach a PWD (with dignity, respect, patience, and understanding that the situation and environment may be overwhelming while giving them), and why it was important to have accommodations for PWDs (people with unseen cognitive disorders deserved the same efforts and opportunities that we gave people with visibly physical disabilities) (Dementia Friends USA 2018). The training was geared towards the general public, with certain videos geared towards their part of the community sector. Sectors included banks, libraries, hospitals, and other types of businesses and social service providers. While this was the shortest training about dementia and DFCs, it had the widest reach and was available to anyone who had a computer to either attend a webinar with a group or watch videos independently. Both resulted in a certificate identifying them as a Dementia Friend.

The Dementia Friends Training previewed the concept of Sector Trainings, discussed later. As stated previously, people needed to either watch the video series on Dementia Friends USA or attend a webinar meeting training, both of which provided the same information (Dementia Friends USA 2019). Both contained an introductory overview of what dementia was and what different sectors of a community could do to accommodate PWDs. The video series allowed people to become a Dementia Friend on their own time and independently. The webinar meeting training, in contrast, was held one or more times a month, depending on how many communities were working towards becoming a DFC and requested a meeting. For example, Susan Frick, a key leader of dementia initiatives through her work at RUSH University’s Medical Center, had her usual monthly Dementia Friends training in November 2020, but she also conducted a training during ECIAAA's retreat within the same month. Both of the trainings had strengths and limitations in practice.

I conducted both types of training and recommend doing the webinar for people who want to learn more about dementia and PWDs. Webinar meeting was as close as we could get to in-person training at that time. Webinars and in-person were great choices because a Dementia Champion or another qualified individual led the presentation, allowing for new Dementia Friends to ask questions that watching videos by themselves may not answer. To become a Dementia Champion, people needed to participate in a more detailed training also run by Susan Frick as a part of her role at RUSH University Medical Center as their key leader in dementia, DFCs, and other dementia initiatives.

Dementia Champions Training

Dementia Champions were people trained, usually by Susan Frick from RUSH University Medical Center in Chicago, to teach Dementia Friendly live sessions. As part of the course, she expanded upon the previous Dementia Friends training and taught us about how to teach a Dementia Friends training ourselves (Frick 2020a). She outlined and differentiated between Dementia Friends USA, Dementia Friends America (DFA), and other interconnected organizations joined together in working towards DFCs. People who took this course must have become a Dementia Friend prior to signing up.

The Dementia Champions training was for people who want to learn more about dementia, DFCs, and DFA. Additionally, it was for people who wished to spread the information they learned from their Dementia Friends training and Dementia Champions training. Not only would they use this information in their own webinars, but Susan Frick and RUSH University also had a shared Google Drive that had resources for the Champions to use in their presentations and other community activities. This training was important because it contextualized the current efforts and leaders in DFCs, dementia friends, and other dementia initiatives.

Dementia Leadership Training

Compared to the previous subsections, this section will be longer because the Dementia Leadership Training was a month-long and was paid for by ECIAAA. During the month of October 2020, I met with other professionals once a week for four hours. When my supervisor initially registered me for the course, my initial impression was that it seemed like an extension of and the next step for the Dementia Friends and Dementia Champions trainings. I assumed it was for advocacy and learning more about how to help PWDs in a systematic way. The agenda and shared summary were broad as well, so I was unsure what to expect. I was partially right as it overviewed the history and culture of dementia care. However, I did not expect it to be geared towards care facility management. The training also contained more information via participant contributions about facility conduct and personal anecdotes than I expected. Most of the other participants in the training were registered nurses and other medical staff that helped in nursing home care facilities or some sort of facility that assisted PWDs.

During the month, I learned not only from the leaders and experts of dementia and dementia care, but I also learned from my fellow participants, who also were experts due to their close work with PWDs. There was one woman who helped me think of dementia care as rewarding work, and it was not as depressing as all the other material I saw made it out to be. There was still sadness, but there was also joy. I had spent so much time reading and watching depressing information about dementia and rarely heard about it in a positive way. The other participants pointed out that if all their experiences with dementia were through research, they would have also thought similarly as I did. However, working with PWDs on a daily basis showed them the brighter aspects of dementia care, and it was not like a Shelf 2.0. Through this month-long training, I learned specific practices on how to care, converse, and support PWDs and their families.

During the Dementia Leadership Training, the presenters defined, provided examples, and listed the significance of personhood and person-centered care, well-being, and communication with PWDs. Combined, these three ideas represented a relatively new way of viewing dementia care that all of these trainings were attempting to spread. The definition of personhood is a view that a person had about themselves or others that was based upon and adds positively or negatively to the meaning, worth, and respect someone has for themselves (Ortigara 2020, 3). Well-being occurs by caregivers providing flexibility and accommodations in order to positively change the PWD's mood and their feeling of independence (Frick 2020b, 18). Communication within dementia care involves "meet[ing the PWDs] in their moment" so that PWDs feel comfortable, not distressed, and not confused when the year or age that they believed they were in did not match our present one (Rothenberg 2020, 2). When brought together, all three were the components of the change from "old culture" to "new culture" in dementia care.

Within contemporary discourse, the discourse shifted from "old culture" to "new culture" of approaching dementia care and how that impacted everyone in the care process, not just the PWD. Old culture referred to past practices and norms enforced by decades of use that maintained the status quo. New culture referred to innovative practices and culture changes challenging old culture by refocusing on personhood. Although today's physicians aimed to phase out the past practices, it was still important and valuable to learn about old culture so that people could learn from them by knowing what to avoid or improve further upon.

First, one example of culture change in the context of personhood was caring for the personhood of the staff (Frick 2020b, 16). In the old culture, medical staff were just cogs in a machine, with the facility higher-ups not taking into consideration the staff's wants and needs (2020b, 16). The facility did not acknowledge that caring for someone, either in a professional or personal relationship, took a toll on a person. In the new culture, the personhood of the staff was just as important as the personhood of the PWD because of the attachment between them (2020b, 16). This was significant because facilities could not afford a high-turnover rate, which was what the old culture's attitude led to. Burn-out would occur, prompting them to do the bare minimum of their job until they found another career path. Aside from a drop in quality and quantity, the quick and successive changes would confuse and upset the PWD, as their bonds continually formed and broke. By acknowledging the staff's personhood, facilities also acknowledged that the facilities were also responsible for the staff's personhood on top of the PWD's personhood.

In addition, another example of culture change in the context of personhood was considering what caring for a PWD involved. In the old culture, caregivers focused on "providing a safe environment and meeting basic needs" for the PWD (Frick 2020b, 12). In the new culture, caring also involved enriching someone's personhood (2020b, 12). This was significant because an established personhood provided a starting point for care that was higher than doing the bare minimum and still expecting someone to flourish without added interpersonal attention for comfortable care. Both culture changes were important to the personhood of the PWD as they provided a sense of safety, security, and trust. It was going beyond changing a PWD's environment or behavior, instead focusing on maintaining personhood.

Next, one example of culture change in the context of well-being was problem behaviors among PWDs. In the old culture, if a caregiver or staff saw a PWD conduct in behavior that they did not deem appropriate or safe, they used restraints or medications to sedate them (Frick 2020b, 14). In the new culture, caregivers saw behavior as a form of communication by PWDs in which they were expressing their needs but were unable to do so in a conventional way. If their needs were not met, it could lead to further frustration and misconstrued behavior on their part (Frick 2020b, 14). This was significant because in order to be flexible in providing accommodations for the well-being of PWDs, facilities needed to identify how PWDs presented problems in order to decrease or nullify it.

Also, another example of culture change in the context of well-being were feelings and emotions of the staff and caregivers in general (Frick 2020b, 15). In the old culture, the “concerns, feelings, and vulnerabilities” of the caregiver did not matter, only the results, which also had to be productive and successful (Frick 2020b, 15). In the new culture, the feelings of the caregivers did matter and should be considered a resource to further excel at their position as a caregiver and strengthen the attachment they had with the PWD (2020b, 15). When considering and being a proponent of the staff and caregivers’ feelings, the new culture brought better treatment for the PWD. This was significant because by acknowledging the well-being of other parties, everyone involved in the dementia care of a PWD could best serve the PWD by knowing not only how the PWD operated and the PWD's current condition but also those of the others involved in care as well.

Additionally, one example of culture change within the context of communication was who knew about administering dementia care best. In the old culture, doctors were the ones who knew the best and the primary people to communicate about PWDs' needs (Frick 2020b, 9). In the new culture, other people who provided direct care were considered experts also since they saw the PWD on a daily basis (2020b, 9). This was significant because unlike some doctors, these medical staff members communicated with PWDs constantly and could see nuances, habits, and other details that could normally be missed in a check-up. They could best articulate the PWDs' needs and advocate for the PWD to communicate directly to others as well.

Lastly, another example of culture change within the context of communication was an "us versus them" mentality that divided the dementia care community. In the old culture, medical staff treated PWDs differently due to their cognitive disorder. Staff believed that PWDs needed to speak, behave, and be provided "different clothing, meals, chairs[, etc.]" than other care recipients (Frick 2020b, 11). While accommodations were understandable and needed, excluding PWD from other care recipients by approaching them differently in terms of speech, mindset, and behavior created a feeling of isolation and othering for the PWD. In the new culture, medical staff should view all care recipients equally and therefore communicate with them equally (2020b, 11). This was significant because the overall sentiment was to not treat PWD as fragile and of needing special protections. Admittedly, the sentiment about equality I somewhat disagreed with because I thought that they were looking at issues of equity rather than ones of equality. For example, not every care recipient in the facility needed the nurses to create a plan on how to communicate with them. Sometimes, staff needed to assist in changing the clothes of patients, but not every PWD needed that type of assistance. By considering everyone's needs equally and implementing changes equitably, the conversation changed. It changed from an “us versus them” mindset into a “we” as a collective mindset.

In all, the culture change in dementia care was important and could be seen through the lenses of personhood, well-being, and communication. All three were interrelated, but they were hard to differentiate at times. Personhood in dementia care was not only the PWD’s meaning, worthiness, and respect but also that of the staff and overall, what care involves. Well-being in dementia care was not just accommodating to PWDs’ mood, it included learning how to successfully identify problem behavior and acknowledging staff feelings. Communication in dementia care was not only from the doctors at a distance from the PWD; communication was also from direct care providers with a mentality to speak with and treat PWDs with equality and/or equity in mind. Although dementia care’s “old culture” and “new culture” still faced some challenges, their anchors of personhood, well-being, and communication provided the foundation in which non-PWDs could start learning to understand PWDs and the dementia care network.

The Toolkit: The DFC Designation

In order to create a DFC, ECIAAA had to follow a four-phase toolkit found on the DFA website. The phases were: Convene, Engage, Analyze, and Act. Phase 1 (Convene) involved finding interest and assessing feasibility of a DFC in the area (Dementia Friendly America 2021a). Area Agencies on Aging (AAAs), the organizations guiding older adult funds distribution to other services in their designated area, would gather key members in order to form and find people for an action team (2021a). Phase 2 (Engage) had key leaders find stakeholders and look for the community’s strengths and limitations that would make it easier or harder to become a DFC (2021a). Phase 3 (Analyze) involved looking at what the community needed and what projects that the stakeholders were passionate to work on for a DFC (2021a). Phase 4 (Act) created plans for these projects by listing objectives, timelines, and leaders and starts implementing these plans (2021a). By following this toolkit, communities could then apply to DFA to get certification.

In our case, I was supposed to show what worked and what did not work throughout our journey in creating a culture change for PWDs and DFCs by following the four-phase toolkit. As of the writing of this capstone, we had not completed the first phase. Below is a further elaboration on the phase progress, even though limited. We went from Macon County, to McLean County, and tentatively Champaign and Vermillion Counties.

Our first target was Macon County, Illinois. They were the home of one of our three Reducing Social Isolation (RSI) committees. We chose them because of the established organizations for older adult services that they contained. We worked with the group leaders, but we somehow could not get a DFC initiative to jumpstart in the area. Thankfully, we had mentioned to all RSI committees that we were planning for a DFC initiative. During the meetings for the other counties, we shared that ECIAAA was interested in other location ideas for DFCs within the 16-county area.

As mentioned in a previous section, we held an Advisory Council and Corporate Board Retreat in November 2020. After the event, an RSI McLean County partner approached us about starting the DFC initiative in LeRoy, Illinois. The partner, a “mover-and-shaker" community leader named Barb Whiteman, worked to help the older adult community and services within the rural area. Barb was the Executive Director for Living Well United, a senior center in LeRoy, Illinois (Sobota 2020). Prior, she was involved with other older adult initiatives in the area. For the next few months, we prepared material to present in front of LeRoy’s city council during one of their meetings. ECIAAA’s Community Liaison Consultant and my DFC project partner, Sheila Greuel, prepared a presentation and handouts for it, while I supported her with gathering data that she had a harder time finding.

At the time, with the strong feedback and collaboration we had with LeRoy, we thought that I could at least be with ECIAAA up to the second or third phase. As we passed 2020 and went on into 2021, it started to look more challenging. The LeRoy City Council did not meet as long or as frequently as anticipated, so we had a strange time window to work with, especially with my contract ending at the end of May 2021. Then, the federal government started to distribute COVID-19 vaccines. This was critical for older adults as they were one of the first groups to get the vaccine. Phase 1a included older adults in congregate settings, such as nursing homes, care facilities, etc. Phase 1b included older adults aged 65+ (Illinois Department of Public Health 2021). As mentioned earlier, Barb was a dedicated and proactive advocate for older adults in LeRoy. When the vaccines were released, she drove busloads of people from LeRoy to Bloomington-Normal. When she was not doing that, she was searching for appointment slots and preparing sign-ups to get older adults appointments. Eventually, during one of our check-in sessions, she regretfully informed us that she could not stretch the resources the community had to an additional project, since COVID-19 needs took priority over DFC visions. On a brighter note, all parties agreed that it was a project worth revisiting once COVID-19 and the vaccines became less urgent.

This left us with our plans with Champaign County and Vermillion County. Like Macon County and McLean County, they also had an RSI committee. Their committee was unique because almost all of the members in that committee were part of two other committees separate from ECIAAA that were related to older adults in the area. While McLean County had Illinois

State University (ISU), Champaign County had University of Illinois Champaign-Urbana (U of I or UIUC). The participation of a major state university brought forth more activity, which was an initial brief worry on ECIAAA's end because the DFC initiative may get lost or pushed aside with other major projects that the university took in. ECIAAA wanted DFCs to be a priority, not a side project. However, RSI Champaign and Vermillion committee leaders were eager to voice their interest. As of the writing of this capstone, we were hoping to start a DFC with Champaign County and Vermillion County together.

This leads us to the current capstone project and paper in which I was creating sector trainings based on my own training for community sectors in Champaign County and Vermillion County. The creation of these sector trainings was a part of the Phase 1 (Convene) organizing efforts. This Phase 1 is meant to bring together potential community supporters, provide a base-line education in the initiative, and build interest. By creating the sector trainings before showing them to the wider audience of the community, ECIAAA could present it to community leaders as a preview of the end goal of creating a DFC. In the next section, I will summarize the contents of each sector training I created for ECIAAA.

Sector Trainings: The Final Product Created

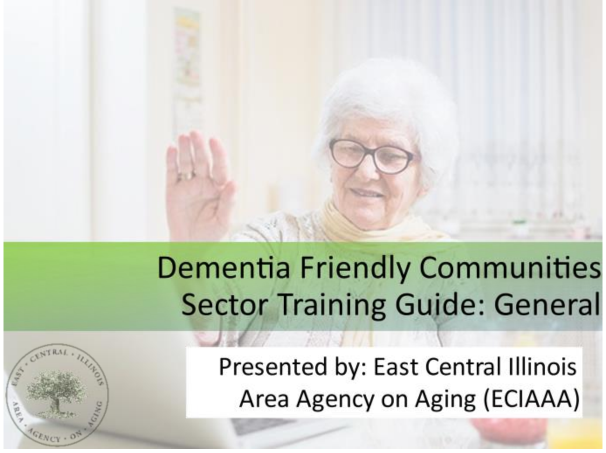
As alluded throughout this capstone paper, Sector Trainings were a series of documents that organizations use in their town and its sectors. The ECIAAA divided the potential members of the DFC into various "sectors" of groups, constituents, agencies, organizations, etc. The sectors that I created PowerPoint presentations for were: General (which was not a sector in itself but was the baseline information that became part of all of the sector trainings), Neighbors and Community Members, Local Government, Businesses, Pharmacies, Banks, Faith Communities, Libraries, Health Care (including First Responders), Legal Agencies, Community-based Services and Supports, Residential and Specialty Care, Hospitals, and Transportation.

The sector training presentations would primarily be distributed in the form of community events or an orientation component. Our Community Liaison Sheila Greuel intended to lead these through “lunch-and-learn” styled meetings. At the end of my term, Sheila became the sole point person for DFC matters. Because of that, we had to discuss how she was going to approach and schedule with sector leaders potential training times that she could present. Because she was only one person with a limited amount of time, she intended to broaden this policy to let others present the material instead of herself. I thought this might be her course of action once she got to a certain point because it was similar to the previous Dementia Champions structure of training one person to teach another group. Rather than going to a neighborhood or a hospital with her materials and presenting it, Sheila could pass the material on to their leaders. For example, Homeowner’s Association Presidents could conduct the sector training, and hospital administrators could conduct it as part of their role in bridging patients and physicians’ needs.

I created the PowerPoint slides under Sheila's guidance. She had over thirty years of experience within the gerontological community, had presented material in a variety of environments and audiences, and had a communications consultant that reviewed her draft material. With all of this in mind, I was extremely thankful for her guidance. Through her advice and input, I was able to create short and impactful PowerPoints for each sector to use.

General

When creating the presentations, General Training was used as a universal slide that would be inserted into the beginning of all other Sector Trainings and was not a stand-alone PowerPoint. I chose this method to make editing easier, so that I did not have to go into every single presentation to edit the same material when making revisions. In the final products, the General Sector will be the same and inserted at the start of all the other Sector Trainings (Dementia Friendly America 2020d). Interestingly enough, the General Sector Training looked very similar to the earlier parts of this document when it comes to describing dementia, DFCs, PWDs, etc. Some ideas mentioned within the beginning parts of a sector guide may repeat due to the general slides having universal information to share, with some sectors delving further into or repeating it (Dementia Friends USA 2019).

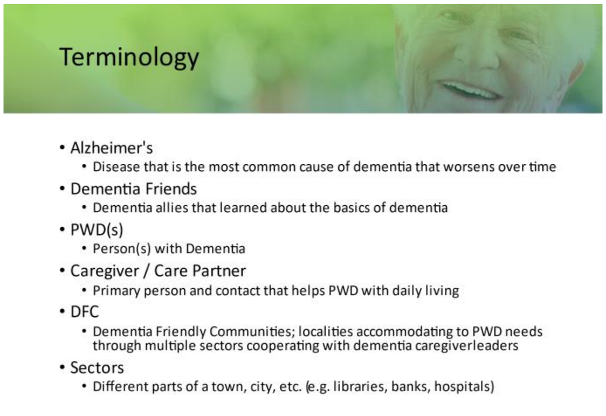


Dementia Friendly Communities
Sector Training Guide: General

Presented by: East Central Illinois
Area Agency on Aging (ECIAAA)

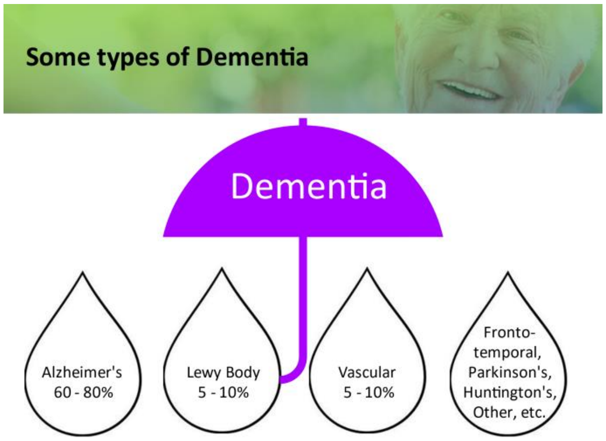
Dementia: loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life.

https://www.alz.org/alzheimers-dementia/what-is-dementia



Terminology

- Alzheimer's
  - Disease that is the most common cause of dementia that worsens over time
- Dementia Friends
  - Dementia allies that learned about the basics of dementia
- PWD(s)
  - Person(s) with Dementia
- Caregiver / Care Partner
  - Primary person and contact that helps PWD with daily living
- DFC
  - Dementia Friendly Communities; localities accommodating to PWD needs through multiple sectors cooperating with dementia caregiverleaders
- Sectors
  - Different parts of a town, city, etc. (e.g. libraries, banks, hospitals)



Some types of Dementia

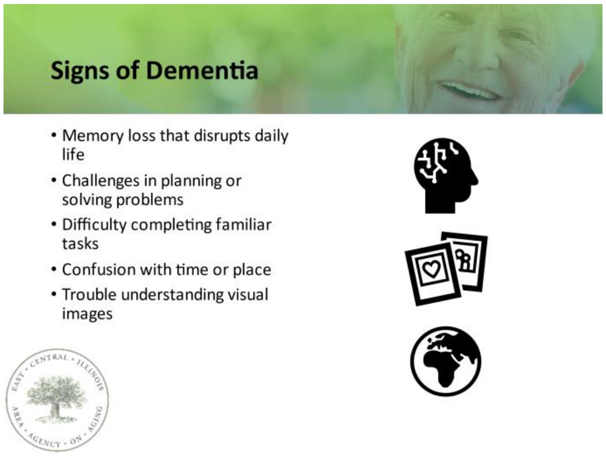
Dementia

Alzheimer's 60 - 80%

Lewy Body 5 - 10%

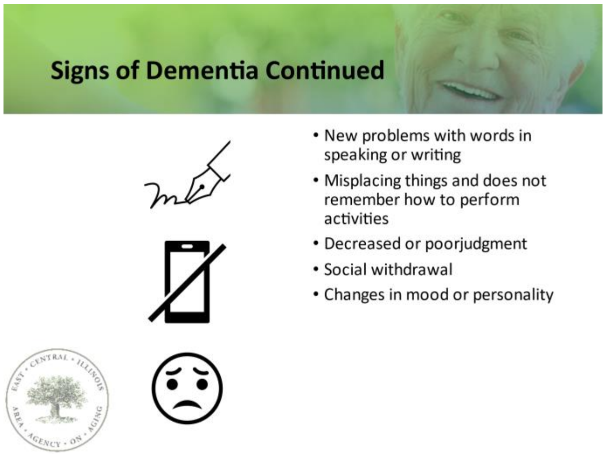
Vascular 5 - 10%

Fronto-temporal, Parkinson's, Huntington's, Other, etc.



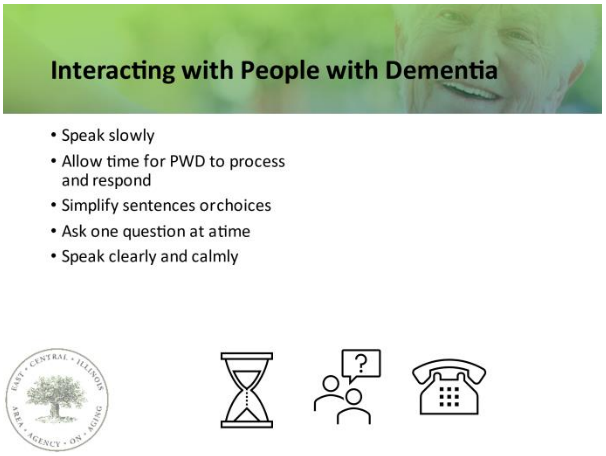
Signs of Dementia

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble understanding visual images



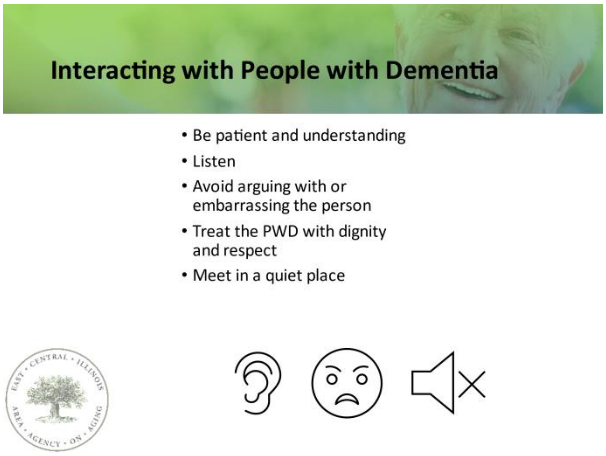
Signs of Dementia Continued

- New problems with words in speaking or writing
- Misplacing things and does not remember how to perform activities
- Decreased or poor judgment
- Social withdrawal
- Changes in mood or personality



Interacting with People with Dementia

- Speak slowly
- Allow time for PWD to process and respond
- Simplify sentences or choices
- Ask one question at a time
- Speak clearly and calmly

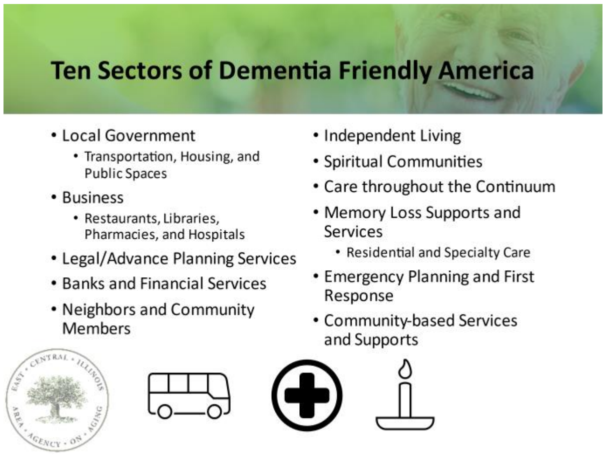


Interacting with People with Dementia

- Be patient and understanding
- Listen
- Avoid arguing with or embarrassing the person
- Treat the PWD with dignity and respect
- Meet in a quiet place

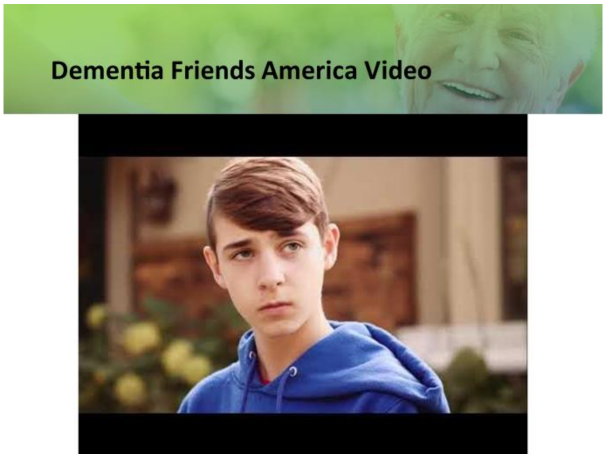
Interacting with People with Dementia

- Be aware of your body language: smile and make eye contact at eye level
- Seek to understand person's reality or feelings
- Apologize and redirect to another environment or subject as needed



Ten Sectors of Dementia Friendly America

- Local Government
  - Transportation, Housing, and Public Spaces
- Business
  - Restaurants, Libraries, Pharmacies, and Hospitals
- Legal/Advance Planning Services
- Banks and Financial Services
- Neighbors and Community Members
- Independent Living
- Spiritual Communities
- Care throughout the Continuum
- Memory Loss Supports and Services
  - Residential and Specialty Care
- Emergency Planning and First Response
- Community-based Services and Supports


Dementia Friends America Video

Neighbors and Community Members

Regarding neighbors and community members, the sector guide I modeled the PowerPoint after had four main sections that showed how people could create an enriching DFC on an individual and local collective level (Dementia Friendly America 2020k). Two key sections of the training were: interacting with PWDs and spreading dementia-friendly principles. As seen in later sector guide sections as well, several of these concepts were recurring from the trainings section, so there were some repeated items but within different contexts and settings. Because neighborhoods are community-based, almost all of the points were interconnected to previous trainings and almost all of the other sector guide sections. It was general and short, supplemented by the General Sector Training that went into all sector trainings. This was to give general public awareness on how to best communicate and interact with PWDs. This training involved the general slides and then encouraged participants to spread their knowledge widely to others in order to create a wide public awareness of the signs of dementia and the benefits of early detection.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be a Homeowner's Association President or a service-oriented group like the Key Club. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

For dementia-friendly principles, it involved neighbors educating themselves on DFC and dementia-friendly practices, sharing what they learned, and applying what they learned by talking about the experience with others in the community (Dementia Friendly America 2020k, 2). To educate themselves, they would start off with attending training events similar to these sector guide presentations. It also would involve going to "advocacy groups, state agencies, and regulators" for information on creating DFC and other dementia-friendly initiatives. Once they established the introductory material, people could spread the information to others in their community. One simple way to do this was to share dementia-friendly websites that provided the means to become an informed Dementia Friend, such as Dementia Friends America. To apply these principles, they could volunteer in other sectors listed below, such as their spiritual community. By learning, sharing, and putting into practice dementia-friendly principles, neighborhoods become better prepared to take these teachings into other sectors that they interact with.

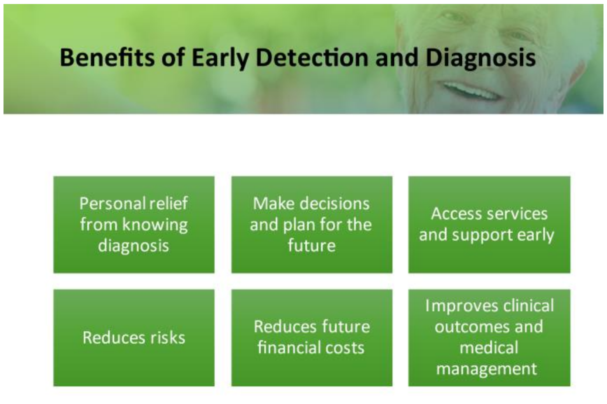
Giving neighborhood sector trainings on how to create a DFC through their sector is important because most neighbors were not educated on recognizing signs of dementia. Community members were not expected to know who in the neighborhood had dementia or not, but being presented with the basics through the Homeowner's Association or other community-driven groups would allow for easier identification. Some members may want to proactively learn more about DFCs. Others may not. However, if a PWD wandered off and needed a search party, the person who did not attend the sector training could be at a loss. For example, the PWD could be in their backyard, and the neighbor could not properly convey to the PWD that people are trying to find the PWD. Depending on their approach, they may upset the PWD. It would be better for neighbors to be educated on how to interact with PWDs and spread dementia-friendly principles.

Dementia Friendly Communities Sector Training Guide: Neighbors and Community Members

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

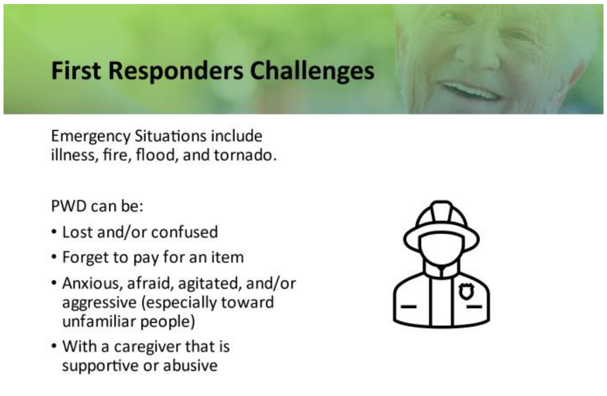
Spread Dementia Friendly Principles

Partner with
- Advocacy groups
- State agencies
- Regulators
- Volunteer to give Dementia Friends presentations
- Share learning experiences
- Spread best practices to promote dementia friendly principles



Benefits of Early Detection and Diagnosis

Personal relief from knowing diagnosis	Make decisions and plan for the future	Access services and support early
Reduces risks	Reduces future financial costs	Improves clinical outcomes and medical management



First Responders Challenges

Emergency Situations include illness, fire, flood, and tornado.

PWD can be:
- Lost and/or confused
- Forget to pay for an item
- Anxious, afraid, agitated, and/or aggressive (especially toward unfamiliar people)
- With a caregiver that is supportive or abusive

Dementia Friends America Video

Local Government

Regarding the local government, the sector guide I modeled the PowerPoint after had listed ways to help PWD be a part of and navigate their community on an infrastructural level and through collective efforts (Dementia Friendly America 2020j). The five settings were: “community planning, home life, mobility, community life, and public safety” (Dementia Friendly America 2020j, 1-4). Because there was an entire sector training on transportation in later sectors and the previous sector training was on neighborhoods, for this sector, it made most sense to only incorporate information from the settings of community planning, home life, and public safety.

For community planning, local governments should gather stakeholders of DFC to listen to and strategize accommodations that they could provide on an infrastructural level. DFC stakeholders included but were not limited to “aging and dementia professionals, older adults, people with dementia, care partners, and the general public” (Dementia Friendly America 2020j, 1). From some of these stakeholders, local governments could learn what to adjust when it came to the city budget, building and other ordinances, specialized training for all community sectors, and other components that helped a city function. The original sector training guide from Dementia Friends America recommended the following actions for local governments:

> Plan for safe, affordable, accessible and dementia capable housing, transportation services, public safety and emergency response, navigable streets, roads and way-finding, businesses, public health, social services, and recreation such as parks and libraries. (Dementia Friends America 2021, 1)

By making these places interconnected to the cause of creating a DFC, local governments would become not only allies but also create tangible support and change for PWDs and their families.

For home life, local governments could help PWDs by working towards a DFC through cooperation and collaboration with the different agencies that are involved in creating and maintaining houses. The key goal was to have homes that were customizable, affordable, and near other sectors, such as transportation and businesses. To reach this goal, local governments should work with “builders/remodelers, architects, occupational and physical therapists, [and] interior designers” to discuss and address the wants and needs that PWDs and their families had. Although the local government cannot realistically meet all these groups or make them watch sector guides closest to their occupation, the local government could still make resources like the Dementia Friends training and the sector guides readily available.

If a local government successfully met with these professionals, local governments should compose a standard practice that can serve as guidelines for these occupations to model after in order to make the city a DFC. Standard practices for housing could include shower installations with chair grabbers and non-slip surfaces, distinctive exits and steps, updated temperature controls and smoke detectors, noise-reducing walling, and contrasting colors so that doors would not blend in with walls (Stoub 2020, 5-13). By creating provisions like these, future employees in the field would have a better grasp of creating a DFC through their construction and architectural work.

For public safety, these training also encompassed disaster planning and emergency response. Like the previous examples, making PWDs and their caregivers part of the planning process was vital in creating procedures to follow during disasters and other emergencies. Local governments could do this inclusionary work by connecting emergency management offices to the aging network. For example, they could collaborate on preparation efforts by making a registry for PWDs so that local governments could take extra measures to make sure that they are safe and supported. Extra measures included collecting updated photographs, creating a volunteer list for search parties, and listing known hazardous areas or other risky places to wander (Stoub 2020, 4). In short, local governments needed to work together with other sectors to make sure that they kept PWDs safe not only with day-to-day activities but with emergencies as well.

Giving local government sector trainings on how to create a DFC through their sector was important because most were bogged down with other initiatives and other bureaucratic tasks and limitations. Providing a pre-made sector training allowed local governments to have an outlined solution to the presented problem. If the stakeholders presenting the DFC sector training could showcase the material well enough, governments would see that some changes were interconnected with the other initiatives or were simple enough to add or implement.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that are already Dementia Friends in this sector, that could present the sector training if Sheila could not, would be a chief social worker or a parks and recreational coordinator. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Local Governemnt

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

Local Government Goals

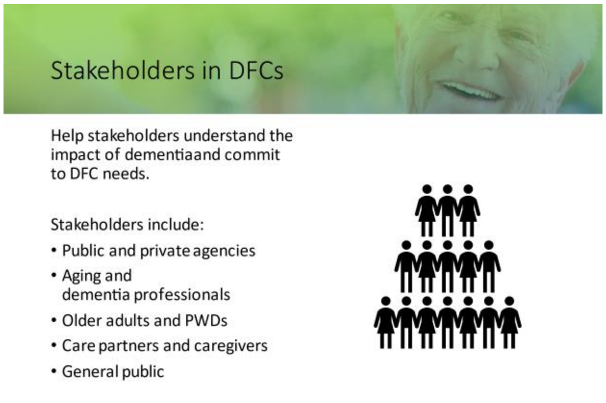
Localgovernments determine community features in our day to-day lives.

Ways to help PWDs: plan and develop:

- Physical infrastructure
- Social infrastructure
- Communities to be more livable for PWDs and caregivers

Dementia friendly practices can:

- Minimize adverse health outcomes
  - Improve qualityof life for PWDs
  - Reduce care partner stress.
- Allows PWDs to remain at home longer, cutting costs tied to stays in health care facilities.
- Benefit local economies as a sustainable community.

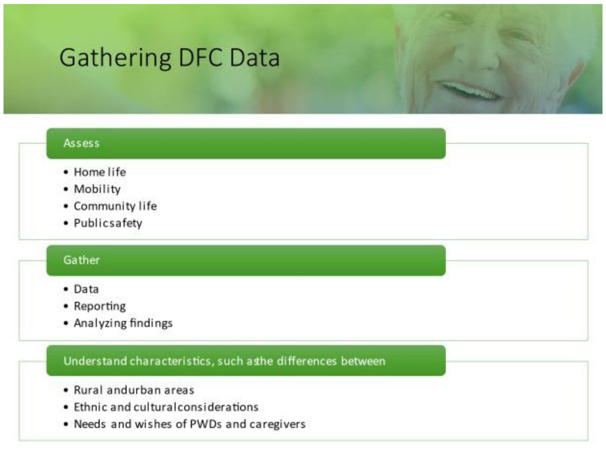


Stakeholders in DFCs

Help stakeholders understand the impact of dementiaand commit to DFC needs.

Stakeholders include:

- Public and private agencies
- Aging and dementia professionals
- Older adults and PWDs
- Care partners and caregivers
- General public



Gathering DFC Data

Assess

- Home life
- Mobility
- Community life
- Publicsafety

Gather

- Data
- Reporting
- Analyzing findings

Understand characteristics, such asthe differences between

- Rural andurban areas
- Ethnic and culturalconsiderations
- Needs and wishes of PWDs and caregivers

Applying DFC Best Practices for Local Governments

Partner with other departments to provide...

- Safe
- Affordable
- Accessible
- Dementia capable

...options in the following community sectors that are the local government's responsibilities:

- Housing
- Transportation services
- Public safety and emergency response
- Navigable streets and roads
- Businesses
- Public health
- Social services
- Recreation such as parks and libraries

How to Apply DFC Best Practices for Local Governments

Prepare to:

- Adjust budgets
- Adopt building or land use changes
- Update products and services
- Change functions or approaches
- Integrate needs of people with dementia into comprehensive planning process

Provide dementia-friendly training and resources to:

- City/county staff
- Emergency responders
- Staff in public health/human services

related to serving and communicating with PWDs

EAST · CENTRAL · ILLINOIS · AREA · AGENCY · ON · AGING

Dementia Friends America Video

https://youtu.be/fdqytCzbF8g

Businesses

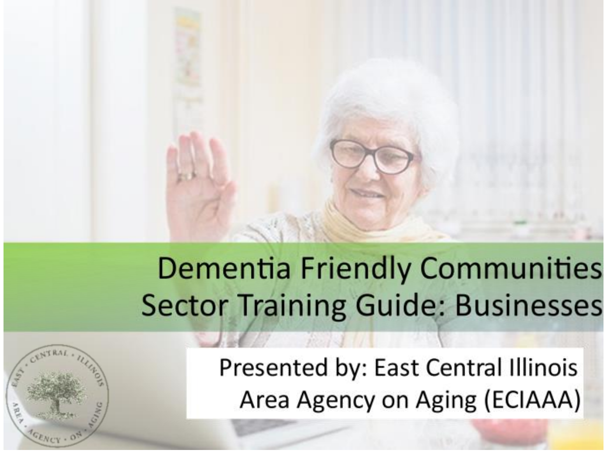
Regarding businesses in the community, the sector guide I modeled the PowerPoint after had emphasized the importance of customer-employee relationships (Dementia Friendly America 2020b). Customers included the PWD as well as their caregiver or other family members. Employees referred to all individuals working for the business that PWDs and caregivers might visit. This training was for businesses without a more specialized training such as the ones for pharmacies and banks below.

Giving businesses sector trainings on how to create a DFC through their sector was important because most were service-oriented. This meant that businesses were dependent on the patronage of others to buy their product or another form of exchange. PWDs, despite some being homebound, still intentionally or not would end up at businesses. Intentionally, they may be with a caregiver or staying in a single place while their caregiver grabbed something. Unintentionally, they may have wandered away from their home and gone somewhere familiar to them or just simply got lost. Although it sounds difficult to adapt and provide accommodations to PWDs, it is a similar initiative to giving such provisions to someone who is blind. We have braille signages, different sidewalk textures and colors, and other adjustments. Both dementia and blindness, although not always exclusive to them, are often associated with older adults and the aging process. The main difference between the two is that the latter is a physical condition while the former is a cognitive impairment. By training staff and other employees in recognizing PWDs and their symptoms, they can better serve their community with equality and equity in mind.

The guide recommended treating PWDs and their caregivers with “dignity and respect” like other customers, in a similar vein of personhood in the Dementia Leadership training (Frick 2020b, 8). In particular, the training recommended that employees build a strong relationship with caregivers. This was important because PWDs might not be able to make major decisions as easily as in the past. By working closely with one another, the caregiver and the business could best serve the PWD’s wants and needs. Once establishing a relationship, the business employees could share the resources in their network that they think would benefit the PWD.

Additionally, businesses must be aware of how the environment of their business impacted their services. For a PWD entering the business, they should see space with adequate lighting and without excessive clutter. In this space, a PWD and their caregiver should be able to find a quiet place separate from the busyness of the business. They need a quiet place to rest or simply separate themselves because a PWD could get overwhelmed with too many stimuli. This quiet place also would allow for employees to talk with them without worrying about another customer eavesdropping on or interrupting the conversation. By using sector trainings to educate employees on making themselves and the space dementia-friendly, they began normalizing these adaptations and implementing them.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be a Human Resource personnel or a manager. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.


Dementia Friendly Communities
Sector Training Guide: Businesses

Presented by: East Central Illinois
Area Agency on Aging (ECIAAA)


More businesses are beginning to respond to the impact of dementia on both **customers and employees**

Customer service and human resource strategies have begun to address how to **meet the needs of customers with dementia and their care partners**

Strategies also begun to address the needs of **employees**.


Customer Perspective

- With 70% of people with dementia living at home, they and their family caregivers will choose businesses that are easy to navigate and that have helpful, aware staff.
- A dementia friendly business is a good business that will help retain existing customers and employees and attract new ones.

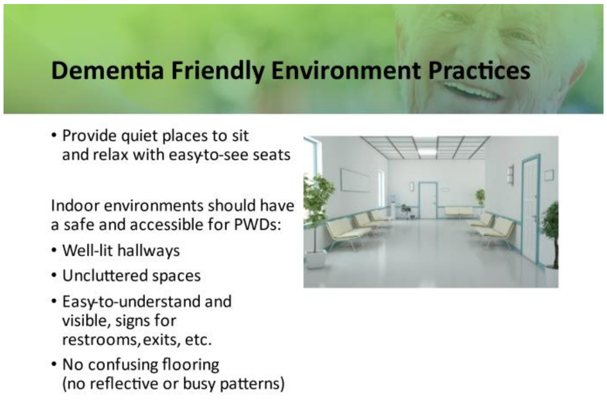

Employee Perspective

- Alzheimer's disease costs U.S. businesses more than $34 billion a year due to:
  - absenteeism by primary caregiver,
  - workday distractions,
  - supervisory time, and
  - reductions in hours.
- Only 6.6 million out of 15 million people that care for someone with Alzheimer's are employed.
- Baby boomers are a valued, experienced segment of the workforce. They are the primary population caring for a spouse or parent with dementia.
- Every $1 companies spend on elder care support reaps a $3 to $14 return.

Dementia Friends America, Sector Guides

Dementia Friendly Business Practices

- Treat all customers with respect and dignity
- Foster a connection with the customer's caregivers, especially with important transactions, to help protect the customer's interests
- Implement new ways to be responsive to needs of customers with dementia and their caregivers



Dementia Friendly Environment Practices

- Provide quiet places to sit and relax with easy-to-see seats

Indoor environments should have a safe and accessible for PWDs:

- Well-lit hallways
- Uncluttered spaces
- Easy-to-understand and visible, signs for restrooms, exits, etc.
- No confusing flooring (no reflective or busy patterns)

Support Employee Caregivers

Help employees by:

- Understanding their two roles as a caregiver and employee
- Connecting employees to community resources
- Establishing schedule flexibility and other policy adjustments
- Asking for employee feedback on company's efforts to support elder caregiver needs.

Dementia Friends America Video

Pharmacies

Pharmacies deserved their own specialized training because PWDs and their caregivers are incredibly likely to patronize them, and they provide some unique and essential services to PWDs. I did not use a specific sector guide as a model when creating the presentation for pharmacies. Instead, I used a guide written by the Greater Manchester Pharmacy Local Professional Network used in the United Kingdom (Greater Manchester Pharmacy LPC 2016). To create a DFC sector, their seven steps were to improve work on: 1) the pharmacy environment, 2) the pharmacy team, 3) public health messages including lifestyle, 4) over the counter medicines, 5) prescription ordering and collection / delivery of medicines, 6) medicine adherence, and 7) resources.

For the pharmacy environment and pharmacy team, the adjustments, adaptations, and alterations were similar to the general business sector training's parts about employees and the business environment. For employees, there were individual and systemic changes. With individual changes, employees were encouraged to become dementia friends and to find ways to support PWDs. With systemic changes, the guide recommended that employees make notes in the pharmacy system about the PWD, including what were a PWD's accommodations and what was the PWD's caregiver's contact information. By getting the caregiver's contact information, employees could call if they needed elaborations, clarifications, or help with the PWD. For the environment, it once again reiterated the need for a quiet place, well-lit areas, and overall accessibility. The guide also prompted pharmacies to reconsider using flooring that is shiny enough to cause confusion, patterned flooring busy enough to cause perception problems, or plain black mats that are dark enough to look like a hole in the ground.

For lifestyles and over the counter medications, these components involved pharmacy staff observation and inquiry of the PWD's health. With public health and lifestyles, employees should ask PWDs and their caregivers if PWDs did or had issues with regular exercise, smoking, drinking, and diet. With over the counter (OTC) medication, the guide instructed staff to make sure that the PWD had not repurchased something that they already bought, had enough money on hand to pay, and had an understanding of the choices of different medications. Unlike prescription drugs, this was harder to track. However, if a pharmacy technician noticed the pattern of a regular client, known to have dementia, buying a large and frequent amount of OTC medication, they should alert other staff to make sure the client was well. The sample instructions listed for OTC medications were common customer service advice; however, the main difference was that pharmacies have a file system that would allow for patient notes so that the pharmacy could let the caregivers know of these concerning patterns. If there were enough notes observing these lapses of memory, then caregivers could follow-up with other healthcare professionals.

For prescriptions and medicinal compliance, both pertained to monitoring closely how PWDs did or did not obtain and did or did not consume prescribed medications. With prescriptions, the guide had many recommendations about the ordering, collecting, and delivering process. When the PWD and/or the caretaker orders medication, the staff could help by sending calendar reminders to make sure that the PWD was not over-ordering or under-ordering, and by extension over-dosing or under-dosing; there was also the worry that the PWD may have completely lost or misplaced their medication. When collecting and delivering medication, the guide advised that the pharmacy accept different forms of proof of identity and that the pharmacy offer a delivery service. With compliance, the guide emphasized making sure to repeat and to be explicit about taking medication. This included asking if they knew what the medication did or what it was for and how to consume it properly and safely. To do this, staff should recommend making reminder charts and specific times to take medication.

For resources, this was another area in which pharmacies could support the DFC vision. Resources included keeping leaflets on dementia on display, referring people to support groups, and referring people to general practitioners.

Giving the pharmacies sector trainings on how to create a DFC through their sector was important because most were a central part to dementia care. Aside from their doctor, the pharmacy staff should be one of the most knowledgeable about the PWD’s medical care plan.

Even though the guide was made in the United Kingdom, almost all of it was applicable to the United States. As a sector, pharmacies play an important part in promoting the care of PWDs by not only giving medication but also sharing resources regarding dementia care. This care gave recently diagnosed PWDs or others who may recognize the symptoms in loved ones the support and information needed to make the best of their situation. Without properly trained and educated pharmacists, dementia care could falter because of the lack of knowledge, support, and overall advocacy.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leader who could present the sector training if Sheila could not would be a manager or another administrative person. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities
Sector Training Guide: Pharmacy

Presented by: East Central Illinois
Area Agency on Aging (ECIAAA)

Seven Steps to Becoming a Dementia Friendly Pharmacy Practice

1. Pharmacy environment
2. Pharmacy team
3. Public health messages (e.g. lifestyle)
4. Over the counter medicines
5. Prescription ordering and collection / delivery of medicines
6. Medicine adherence
7. Resources

Source: Framework of elements developed
by Greater Manchester Pharmacy Local Professional Network in the United Kingdom

Dementia Friendly Environment Practices

Provide quiet places to sit and relax with easy-to-see seats

Indoor environments should be safe and accessible for PWDs

- **Well-lit** hallways
- **Uncluttered** spaces
- **Signs** for restrooms, exits, etc. are easy to understand and see
- Simple **flooring** (without reflective or busy patterns)

Pharmacy Team

Pharmacy team members should:

- Be trained as a **Dementia Friend**
- Discuss how to better **support** PWDs
- Add a **system note** about support methods for individual patients
- Have routinely updated **contact details** of a relative or caregiver

Public Health and Lifestyle

Provide advice and information about:

- Regular exercise
- Smoking
- Alcohol
- Diet

Over-the-Counter Medications

- Plan how to deal with patients who make **repeated requests** for items already purchased
- Check a patient's **medication changes** with them
- Help a patient **choose** between medications through education and symptoms needing managed.

Prescription Ordering, Collection and Delivery

- Have pharmacists help set **calendar reminders**
- Plan how to help patients who are **ordering** prescription items more often than indicated – are they **overdosing or losing their medication**? Check with the prescriber
- Have another system for checking **proof of identity** if a patient cannot remember their address
- Offer a **delivery service** with Dementia Friendly-trained drivers
  - Call patients to remind them when the delivery driver is coming and deliver at the same time each week with a note for the patient

Medication Adherence

- Explain medications and check that the patient **understands** you, e.g., show the patient the medications
- Provide adherence **aids**, e.g., reminder charts, bubble packs, and medication organizers, and medication dispensary units
- Put **specific times of intake** on medication labels, e.g., breakfast
- Include the **indication** on the medication label, e.g., for pain relief

Resources

Provide

- **Leaflets** about dementia
- Information about **local support groups** for patients and caregivers
- Websites and phone numbers for **national support groups**

Refer patients to the pharmacist or general practitioner if patient is displaying symptoms of dementia

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Dementia Friends America Video

Banks

Regarding banks, the sector guide I modeled the PowerPoint after outlined warning signs, guidelines, communication skills, and customer service skills when it came to the financial decisions and actions that PWDs and their caregivers made (Dementia Friendly America 2020a). The bank and bank employees’ role in this DFC process would be to provide accommodating services to current clients with dementia and to identify the early signs of dementia among their customers. This would protect both the banks and the PWDs from financial issues such as “unpaid expenses, squandered resources, avoidable guardianship, and financial abuse, neglect, or exploitation” (Dementia Friendly America 2020a, 2). By examining the outline of the Banks

Sector Training PowerPoint, bank employees could better prevent or minimize financial issues such as these. Such preventative actions are important in creating a DFC through this sector because money is everywhere and a part of almost every major or service-oriented transaction within the rest of the community striving to be dementia-friendly.

For warning signs, they were important for bank employees to know so that they could identify money mismanagement and early onset dementia within the financial institute. Six warning signs of dementia within a financial context are: lapses in memory, disorganization, worsening money management skills, decline with basic math skills, difficulty grasping financial concepts, and poor judgment with finances (Dementia Friendly America 2020a, 4). With all six warning signs, they all involved a previously established starting point, and people could see the decline of these certain abilities and activities in real time. With lapses in memory and disorganization, this included misplacing or neglecting document records, which could lead to missed appointments and confusion as well as repetition of payments. With declining math and money management skills, this included forgetting or incorrectly filling out paperwork like checks and being unable to do basic arithmetic. With difficulties in understanding financial concepts and financial judgment, both involved the decline of comprehension that they may have had in the past. In particular, poor financial judgment could lead to “drastic changes in investments […] or […] get rich-quick schemes” (Dementia Friendly America 2020a, 4). Another batch of warning signs to monitor were issues of financial abuse by a PWD’s caregiver, family member, or other outside individual. This included but was not limited to a third party’s financially abusive behavior by doing actions such as: making unusual amounts of withdrawals, investing chaotically, preventing the bank from contacting the PWD, and intimidating the PWD from speaking with the bank (Dementia Friends America 2021, 5). With these warning signs, employees could better monitor the consistent or inconsistent activities with their clients, contributing to a dementia-friendly community through their sector.

For guidelines on financial challenges that PWDs may experience in a bank, guidelines revolved primarily around someone advocating for the PWD. This advocate would try to see how best the PWD could care for themselves or have another person involved in financial matters. The ideal situation would be the PWD making most decisions, when possible, until it was too difficult for the PWD. Although assessing PWDs' attentiveness would not be hard to gauge when banks go through the General portion of the sector training, bank employees could prepare for the eventuality overall by asking for a secondary contact and for a power of attorney or trust. The PWD and their contact or trust should be kept up to date on the current standings that the PWD has with the bank. In turn, the other party should inform the bank on changes on their end as well. In this way, the bank could better follow guidelines and prepare for the eventual decline in dementia and for the protocol on how to do business with someone with a disability in general.

For communication skills, interacting with PWDs in a bank setting could be split into two five-step processes. First, the bank employee must pace speech slowly, simplify concepts, ask straightforward questions, speak with understanding, and avoid arguments and embarrassment. Second, the bank employee must treat the PWD with dignity, provide a quiet place, be aware of body language, try to understand the PWD's reality and feelings, and apologize if the PWD gets upset and try a different route of communication (Dementia Friendly America 2020a, 9). By following these protocols within a bank setting, bank employees would better identify, understand, and help a PWD.

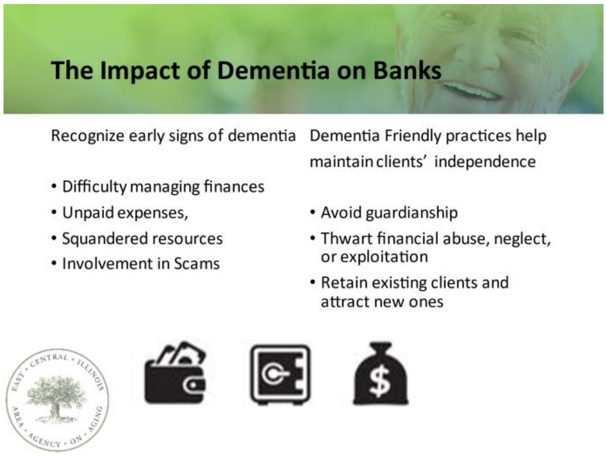
For customer service skills, bank employees should make PWDs feel comfortable, independent, and heard. With regards to comfort, banks should follow recommended indoor settings for PWDs. This would include quiet places, good lighting, no clutter, and clear signage. Additionally, comfort for the PWD would involve an employee possibly being uncomfortable with frank discussions. Namely, the bank employee should ask the PWD if they could write down their disability in their records. This note in the system would make the bank aware that they need to create accommodations accordingly. With independence, the main thing one should give a PWD is the ability of choice.

Giving banks sector trainings on how to create a DFC through their sector was important because financial abuse is easy to overlook if the PWD and bank employees cannot recognize it. By knowing the warning signs, guidelines, communication, and customer services skills needed to identify financial abuse or mismanagement, the PWD could maintain some autonomy and personhood. They could control where their money goes as their health declines in the future as well as how and if the money was spent correctly in the present. Through sector trainings, community leaders would give bank employees tools that they could use for everyday business.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be an Asset Manager or a Relationship Manager who bridges the needs of clients to the staff. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Banks

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)



The Impact of Dementia on Banks

Recognize early signs of dementia

- Difficulty managing finances
- Unpaid expenses,
- Squandered resources
- Involvement in Scams

Dementia Friendly practices help maintain clients' independence

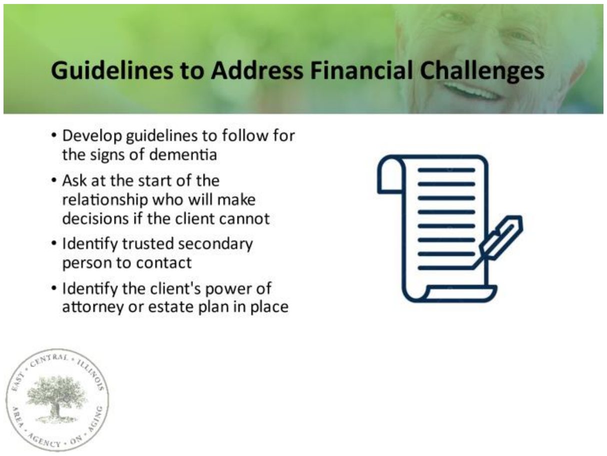
- Avoid guardianship
- Thwart financial abuse, neglect, or exploitation
- Retain existing clients and attract new ones

Six Warning Signs Specific to Money Management

- Lapses in memory
- Disorganization
- Worsening money management skills
- Decline with basic math skills
- Difficulty grasping financial concepts
- Poor judgment with finances

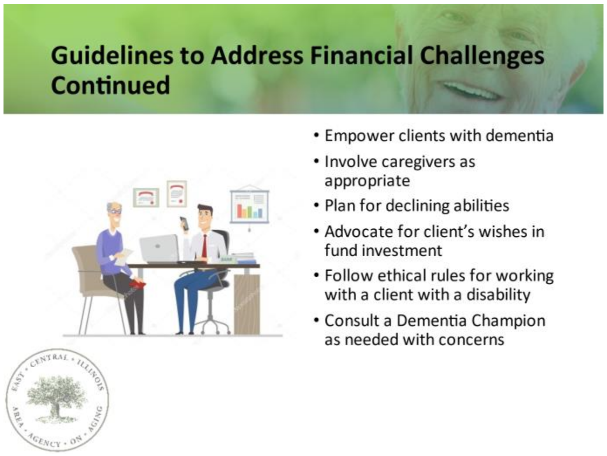
Signs of Financial Abuse

- Misuse of money by a third party
- Unusual account withdrawals
- Drastic shifts in investment style
- Inability to contact customer
- Isolation from friends/family
- Reluctant to speak in front of caregiver



Guidelines to Address Financial Challenges

- Develop guidelines to follow for the signs of dementia
- Ask at the start of the relationship who will make decisions if the client cannot
- Identify trusted secondary person to contact
- Identify the client's power of attorney or estate plan in place



Guidelines to Address Financial Challenges Continued

- Empower clients with dementia
- Involve caregivers as appropriate
- Plan for declining abilities
- Advocate for client's wishes in fund investment
- Follow ethical rules for working with a client with a disability
- Consult a Dementia Champion as needed with concerns

Dementia Friendly- Customer Service

Create conditions that help customers feel comfortable sharing their needs

Help them remain for as long as possible

- independent
- able to make their own decisions

Provide a dementia friendly environment with that is safe and accessible with:

- quiet places to sit and relax;
- well-lit hallways;
- uncluttered spaces;
- pictures and signs that identify areas such as restrooms.

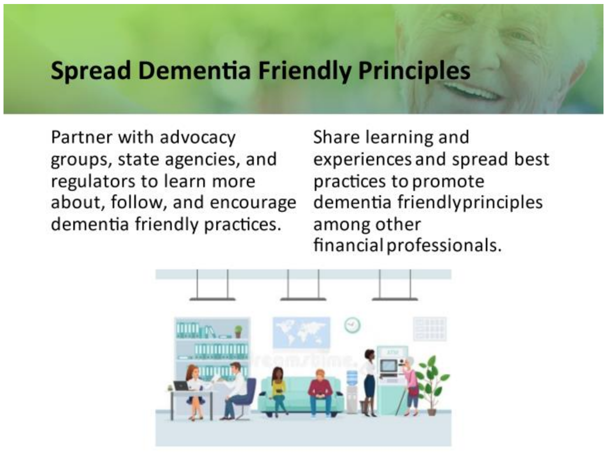
Dementia Friendly- Customer Service Continued

- Make suitable recommendations and put needs of client first
- Listen to client and care partners
- Act lawfully and ethically
- Keep records of communications and needs to aid future interactions
- If the person discloses that they have dementia, ask if it can be recorded
- It is much easier to assist and support a person who has made this known

Dementia Friendly- Products and Services

Provide alternate security/fraud prevention methods

- Financial planning
- Good advance planning
- Be alert and report financial abuse



Spread Dementia Friendly Principles

Partner with advocacy groups, state agencies, and regulators to learn more about, follow, and encourage dementia friendly practices.

Share learning and experiences and spread best practices to promote dementia friendly principles among other financial professionals.

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Spiritual Communities

Regarding spiritual communities, the sector guide I modeled the PowerPoint after emphasized the education, engagement, and environment from the spiritual community

(Dementia Friendly America 2020e). Education came from learning of ways to accommodate for the PWD through the PWD's family and resources the family recommended. Engagement came from both a group level and an individual level. Environment came in the form of supporting the family of the PWD directly by adapting the place of worship to become more dementia-friendly and by looking out for caregivers' stress. Please note that I attempted to make the sector training more geared towards all spiritual communities, but there may be examples used that are Christian-leaning, due to the material that I modeled the presentation after.

For educating the spiritual community, they recommended educating fellow attendees based on the shared knowledge of the family and the services volunteered by the spiritual community. With the family, the original guide recommended that the family of the PWD speak and share their experience or for the PWD to share their experience themselves. I kept it on there, since certain circumstances and people could make it work. However, I thought that putting the families and PWD on the spot, even with asking ahead of time, would put pressure on them to be vulnerable, especially if they were new attendees themselves or newly diagnosed. Dementia and other disabilities are hard to divulge because people do not know how others will react or process the information. Through making this particular sector guide, it made me reflect upon how there is a fine line between giving people the chance to share their story and pushing the responsibility of educating the other attendees into the hands of the PWD and their families.

With the spiritual community themselves, they could learn with a more hands-on approach by asking how they could best support and serve the family of the PWD. Instead of asking the PWD's family to share with everyone, members could instead learn about dementia while they volunteer to relieve some of the pressure and duties caregivers have. As long as everyone in the spiritual community is not doing this simultaneously, the PWD's family could move at their own pace of teaching people about their life experiences while having assistance and support. The spiritual community members could help with transportation and other preparations for attending service. They could give brief respite for the caregivers by keeping the PWD company while the caregivers do other errands or tasks that would normally be difficult to do while caring for the PWD. Also, the fellow attendees could either bring the PWD's family a service recording or accommodate the possibility of the PWD talking or walking when they should not during service. Although these seemed to be just simple tasks, the spiritual community could learn while providing truly tangible and needed help to the family of the PWD.

For engaging the spiritual community, this should be done on a group and individual level. On a group level, there were several ways to include the PWD and their family in the place of worship's activities. The spiritual leader could make short and simple services with easy prayers and songs (Dementia Friendly America 2020e, 3). The spiritual community could also host activities outside that "all ability levels" could join in doing, like an outdoor cookout (Dementia Friendly Communities 2020e, 3). If there were enough members to do so, they could make a memory café for the PWD and a support group for their families. A memory café is a separate space for PWDs and their caregivers to mingle with other PWDs and caregivers (Memory Café Directory 2021). Some would involve physical or mental activities, while others would have crafts and music. The memory café is there to create new friendships and share old memories. There is no clear formula of what makes a good café, just as long as everyone involved feels like they made a connection or had a moment of peace. On an individual level, the guide encouraged spiritual community leaders to connect a PWD and their family to other members who were open-minded and open-hearted to help them adapt. Leaders and key members should also make an effort to learn more about the structure of the PWD and their family’s spiritual beliefs. Through collective efforts and effective leadership, engaging the spiritual community to embrace and create a space for the PWD and their families would lead to a DFC.

For adapting the environment of the spiritual community, fellow members could make the area and themselves dementia-friendly in simple ways. To help acclimate PWDs to the environment, everyone could wear name tags and the building could have clear signs to key places like bathrooms. Fellow attendees could also do classic person-centered care techniques by focusing on the strengths instead of the limitations of the PWD and by providing a quiet area. As mentioned before, helping relieve pressure from the caregivers would be beneficial. This could be done by finding ways in which the family with the PWD could worship from home as a more comfortable environment, such as the aforementioned recording of a service. Members should also provide an atmosphere in which they “welcome, acknowledge, and support” the PWD and their loved ones (Dementia Friendly America 2020e, 3). These were some ways to change the environment to best fit the needs of the PWD; conversely, learning to identify stress patterns of the PWD and their caretaker is an equally important part of fostering a good, dementia-friendly environment.

For identifying PWD’s and caretaker’s stress in a spiritual environment, the symptoms are similar to other high-stress or tiring situations. Because of the caretaker’s “anxiety about the future” and their depression of their current situation, some families deny the dementia diagnosis and assume that the PWD’s health will improve (Dementia Friendly America 2020e, 3). Once they get past the denial, the anger, social withdrawals, and irritability begin to appear as they adjust to the life of becoming a caregiver. Without the support from the spiritual community and other sectors in the town, the caregiver could burn out, feel sleepy, lose concentration, and have other health problems. By recognizing these signs in the spiritual community environment, leaders and key members could better take care of their fellow attendees.

Giving spiritual communities sector trainings on how to create a DFC through their sector is important because most would be eager to help their fellow attendee. With sector trainings, leaders and key members of the spiritual community could best serve their congregation through education, engagement, and the environment. Education from the voices of the family could bring forth an introduction to the lives of families with a PWD. Engagement on a group and individual level would promote inclusivity. For the environment, alterations to the place of worship would help PWDs and their families greatly. Fellow attendees could also look at caregivers for symptoms of stress and help identify a need to be met and supported. Through spiritual communities' sector training, people could learn how to take their beliefs and see how they could best support PWD and their families with their spirituality as well.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be a pastor or congregate leader. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Spiritual Communities

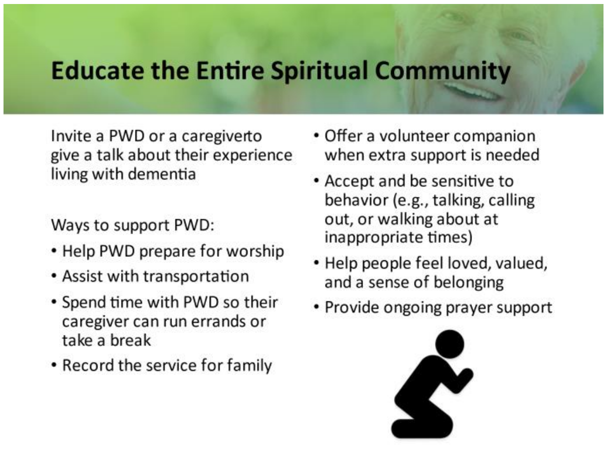
Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

Dementia and Spirituality

DFCs that support one's spiritual needs can provide an important form of respite.

As welcoming, compassionate environments, they offer families coping with dementia opportunities for meaningful engagement and spiritual connection.

Through dementia friendly practices, entire spiritual communities can embrace and uplift PWDs and their care partners.

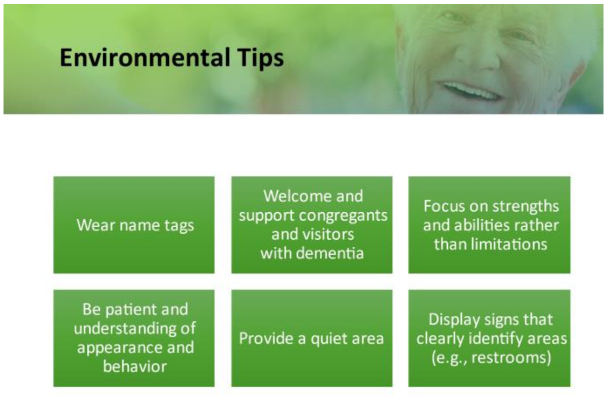


Educate the Entire Spiritual Community

Invite a PWD or a caregiver to give a talk about their experience living with dementia

Ways to support PWD:

- Help PWD prepare for worship
- Assist with transportation
- Spend time with PWD so their caregiver can run errands or take a break
- Record the service for family
- Offer a volunteer companion when extra support is needed
- Accept and be sensitive to behavior (e.g., talking, calling out, or walking about at inappropriate times)
- Help people feel loved, valued, and a sense of belonging
- Provide ongoing prayer support

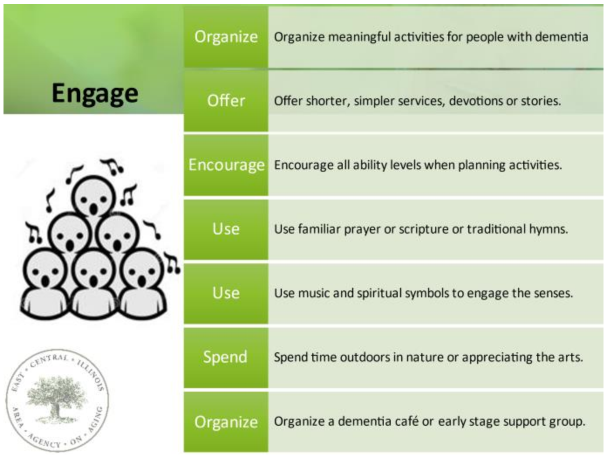


Environmental Tips

- Wear name tags
- Welcome and support congregants and visitors with dementia
- Focus on strengths and abilities rather than limitations
- Be patient and understanding of appearance and behavior
- Provide a quiet area
- Display signs that clearly identify areas (e.g., restrooms)

Environmental Tips

- Support caregivers to do self-care and accept help
- Offer support frequently, even if it is turned down
- Help care partners worship at home
- Encourage respite care for a break
- Form a caregiver support group

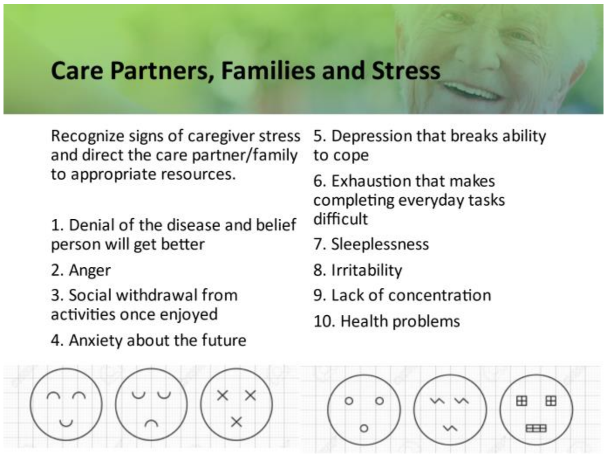


Engage

Organize	Organize meaningful activities for people with dementia
Offer	Offer shorter, simpler services, devotions or stories.
Encourage	Encourage all ability levels when planning activities.
Use	Use familiar prayer or scripture or traditional hymns.
Use	Use music and spiritual symbols to engage the senses.
Spend	Spend time outdoors in nature or appreciating the arts.
Organize	Organize a dementia café or early stage support group.

Individualize

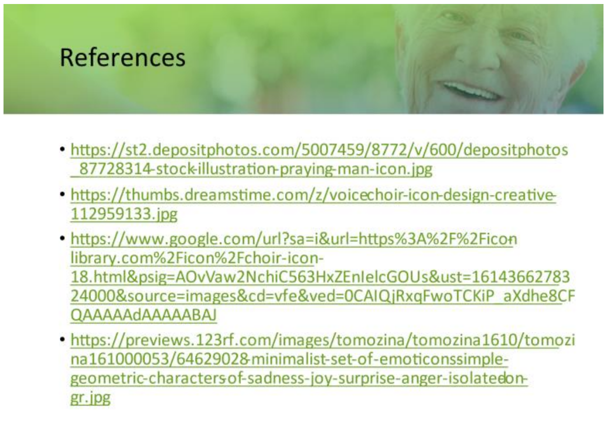
- Build support relationships by linking people with dementia and their caregivers with empathetic individuals within the congregation
- Learn how the spiritual beliefs of the person with dementia and his or her care partners may affect their perceptions and experience of dementia
- Be attuned and open-minded to the way the person talks about his or her spirituality



Care Partners, Families and Stress

Recognize signs of caregiver stress and direct the care partner/family to appropriate resources.

1. Denial of the disease and belief person will get better
2. Anger
3. Social withdrawal from activities once enjoyed
4. Anxiety about the future
5. Depression that breaks ability to cope
6. Exhaustion that makes completing everyday tasks difficult
7. Sleeplessness
8. Irritability
9. Lack of concentration
10. Health problems



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Libraries

Regarding libraries, the sector guide that I modeled the PowerPoint after mainly discussed library programming and services that they could do for PWD and their caregivers (Dementia Friendly America 2020i). Programming included awareness education about dementia and Alzheimer’s, support groups for PWD and their caregivers, book clubs, and memory cafés. For services, libraries could deliver items, drive a book mobile, and offer other services that would send books and other library material to places where PWD live. This could be with “senior living communities, adult day settings, congregate living settings, and homebound patrons” (Dementia Friendly America 2020i, 3).

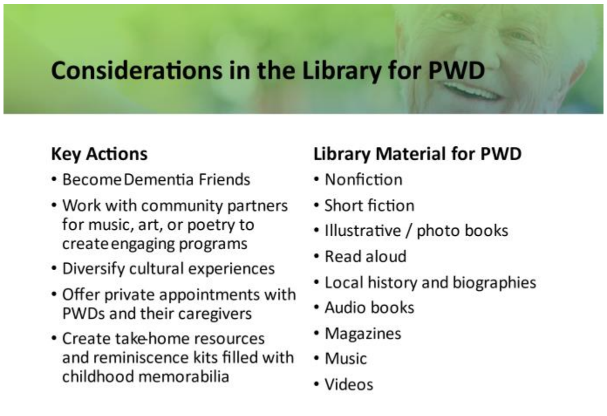
Related to the rest of my experience with ECIAAA, library involvement in the older adult community is important to establish and maintain. During the pandemic, both the Bloomington Public Library and Normal Public Library in Bloomington-Normal had provided similar delivery services as listed above to local nursing homes and other older adult living facilities. When we updated the McLean County RSI Committee on the status of our DFC efforts, they also became interested in the topic and have slowly been incorporating more dementia-friendly practices. If the libraries were already doing what was suggested for a DFC unintentionally, I am confident that they would be a huge proponent and reason for the success of a future DFC initiative in McLean County.

Giving libraries sector trainings on how to create a DFC through their sector is important because most are resource-centered. The goal of libraries is to provide and offer as many materials as possible. If DFC practices started appearing in libraries, they would gain the interest of PWD and their caregivers as a safe and supportive space to go to. Some librarians from a DFC meeting I attended said that they recently developed a memory café, and another said they had a support group. With sector trainings, libraries had a better idea on how to approach PWDs and how to best provide the wanted and needed resources.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be a library director or Public Relations Specialist (McKay 2019). Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities
Sector Training Guide: Libraries

Presented by: East Central Illinois
Area Agency on Aging (ECIAAA)



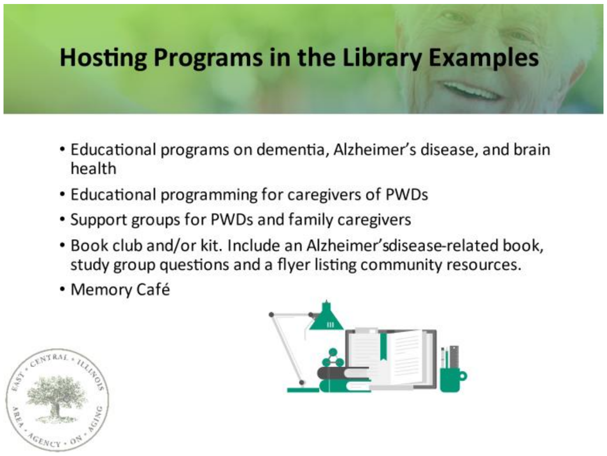
Considerations in the Library for PWD

Key Actions

- Become Dementia Friends
- Work with community partners for music, art, or poetry to create engaging programs
- Diversify cultural experiences
- Offer private appointments with PWDs and their caregivers
- Create take-home resources and reminiscence kits filled with childhood memorabilia

Library Material for PWD

- Nonfiction
- Short fiction
- Illustrative / photo books
- Read aloud
- Local history and biographies
- Audio books
- Magazines
- Music
- Videos



Hosting Programs in the Library Examples

- Educational programs on dementia, Alzheimer’s disease, and brain health
- Educational programming for caregivers of PWDs
- Support groups for PWDs and family caregivers
- Book club and/or kit. Include an Alzheimer’sdisease-related book, study group questions and a flyer listing community resources.
- Memory Café

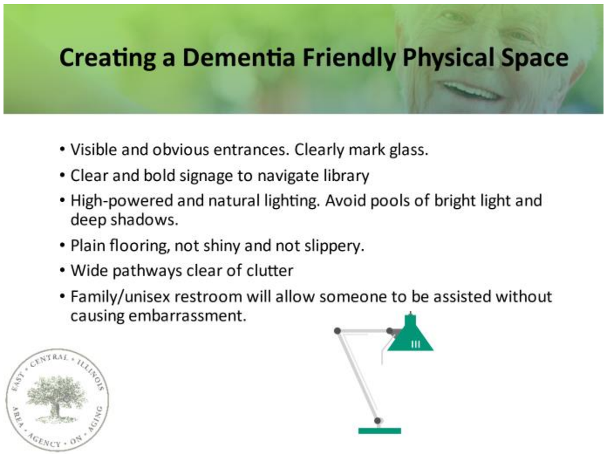
Taking Library Services and Materials to the Community

What to Do

- Offer programs using library materials E.g., “Tales and Travel Memories” program
- Offer a bookmobile
- Provide a read-a-loud program
- Deliver library materials to homebound patrons

Places to Be

- Senior living communities
- Adult day settings
- Congregate living settings
- Homebound patrons



Creating a Dementia Friendly Physical Space

- Visible and obvious entrances. Clearly mark glass.
- Clear and bold signage to navigate library
- High-powered and natural lighting. Avoid pools of bright light and deep shadows.
- Plain flooring, not shiny and not slippery.
- Wide pathways clear of clutter
- Family/unisex restroom will allow someone to be assisted without causing embarrassment.

Health Care

Regarding health care, the sector guide that I modeled the PowerPoint after covered a wide array of topics that impacted the PWD and their families when it came to medical treatment (Dementia Friendly America 2020f). These revolved around the PWD and living healthy, planning with the caregiver, and promoting positive behavioral health. Living health involved adhering or avoiding certain practices for medicinal and non-medicinal practices. Planning with the caregiver could involve the health care staff looking after the caregiver and making plans with them regarding the PWD’s prognosis. Plans include promoting positive behavioral health, looking for symptoms, and finding treatment for PWDs. Although there are specific facilities and doctors specializing in PWD and dementia care, other health care staff should have a basic education on what they could do to support the PWD and their families.

For living healthy, caregivers and other care providers should focus on both medicinal and non-medicinal methods when it comes to the well-being of the PWD. With medicinal methods, the medication is usually not treating dementia itself, merely some symptoms. The guide stated that, “[t]here is no FDA-approved medication for Behavioral and Psychological Symptoms of Dementia” (Dementia Friendly America 2020f, 4). Because most cognitive medications were not FDA-approved, most medications that PWDs take were vitamins and herbal medicine. If they were taking a medication that was supposed to treat cognitive symptoms and was failing to do so or making it worse, the PWD should gradually or immediately stop taking the medication. With non-medicinal methods, they were usually used to combat psychological, physical, or “sensory issues or impairments” (Dementia Friendly America 2020f, 3). These methods included but were not limited to exercising, eating healthy, socializing, and not consuming tobacco or alcohol. By teaching health care staff the medicinal and non-medicinal treatments of dementia, they could better understand how to create a DFC.

For planning with the caregiver, health care providers should make sure that they have support and can collaborate with them on determining care for both the advanced stage and the end-of-life stage. With the caregiver’s needs, health care staff should have a list of resources ready, such as local support groups, respite care, and caregiver education. Staff should also make sure to support caregivers in doing self-care, voicing their needs, and believing that they are not alone in this care process. They have friends, family, staff, and others to help with taking care of the PWD. With the late-stage and/or end-of-care plans, health care staff and the caregiver have numerous items to prepare and discuss regarding the care of the PWD. The health care staff should ask what the caregiver would prefer to do about "advance care documents, healthcare directive, legal and financial planning, Power of Attorney," and other paperwork (Dementia Friendly America 2020f, 4). Depending on the stages, health care staff should also plan with the caregiver about Provider Orders for Life Sustaining Treatment care and hospice care, for late-stage care and end-of-life care, respectively. By keeping the needs of the caregiver in mind, health care staff could promote a DFC where not only the PWD has support but also their family and friends.

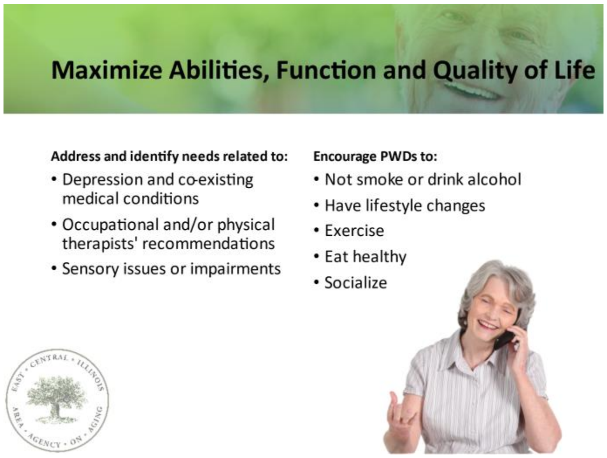
For promoting positive behavioral health, there are a few symptoms and subsequent treatments to look out for. Behaviors, as mentioned in the training section, are a cause of some stimuli in the environment or situation that the PWD is in. This was how PWD conveyed unmet needs, overstimulation, and other irritants (Rothenberg 2020, 11). One way that health care staff could help the caregiver with the PWD is to teach them how "to improve communication, validation, and redirection" (Dementia Friendly America 2020f, 4). Some methods included practicing ability-focused care, exercising through engaging and rhythmic activities, and providing capability-compatible routine tasks for the PWD to do. Health care staff should know more about and practice positive behavioral health methods because it further supports DFC initiatives by doing person-centered care.

Training the broader health care sector on how to create a DFC through their sector was important because most were not as equipped as their dementia-specialized counterparts. They were responsible for the PWD living in a healthy manner, for the caregiver overwhelmed by choices, and for both the PWD and the caregiver's positive behavioral health. By knowing the basics of dementia, the signs to look for, and the resources to act further, health care staff contributed to the DFC initiative.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. A potential leader that could present the sector training if Sheila could not would be a Human Resources individual. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Health Care and First Responders

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)



Maximize Abilities, Function and Quality of Life

Address and identify needs related to:

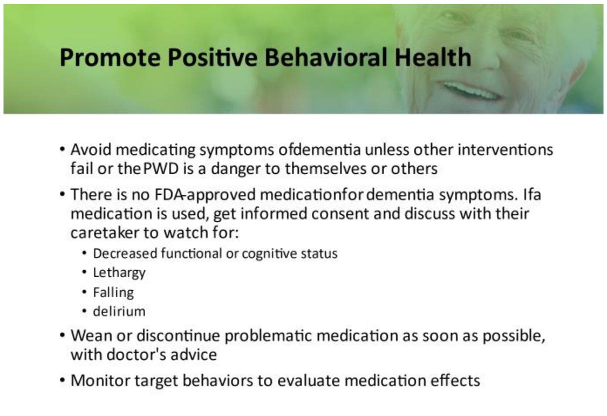
- Depression and co-existing medical conditions
- Occupational and/or physical therapists' recommendations
- Sensory issues or impairments

Encourage PWDs to:

- Not smoke or drink alcohol
- Have lifestyle changes
- Exercise
- Eat healthy
- Socialize

Medication Therapy and Chronic Disease Management

- Review medications
- Create or simplify medicine regimens
- Have a detailed conversation with your primary care physician before taking any new medications
- Reassess medications, including those for cognitive symptoms; consider a slow taper if continued benefit is unclear



Promote Positive Behavioral Health

- Avoid medicating symptoms of dementia unless other interventions fail or the PWD is a danger to themselves or others
- There is no FDA-approved medication for dementia symptoms. If a medication is used, get informed consent and discuss with their caretaker to watch for:
  - Decreased functional or cognitive status
  - Lethargy
  - Falling
  - delirium
- Wean or discontinue problematic medication as soon as possible, with doctor's advice
- Monitor target behaviors to evaluate medication effects

Promote positive behavioral health:

Identify and address:

- behavior as a way to communicate:
- unmet needs
- reversible conditions
- too much clutter or stimuli
- care partner tactics on self-care, respite, and education

Non-pharmacologic approaches to reduce symptoms:

- focus on abilities rather than limitations
- plan activities that engage interests and repetitive motion.
- plan tasks that match their capabilities.
- access training for care partners to improve communication, validation, and redirection.
- routine is essential.

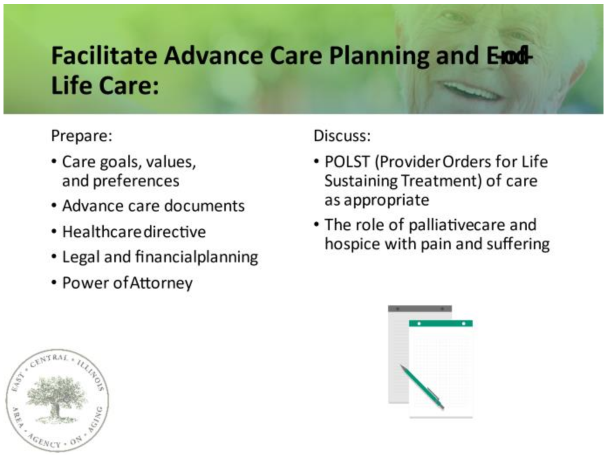
Assess and Support Care Partner Needs:

Look at local resources

- Support groups
- Respite care
- Care partner education and training programs
- Care partner coaching.

Encourage care partners to:

- Provide self-care
- Make your needs known.
- Ask for help from family and friends
- Believe you are not alone



Facilitate Advance Care Planning and End-of-Life Care:

Prepare:

- Care goals, values, and preferences
- Advance care documents
- Healthcare directive
- Legal and financial planning
- Power of Attorney

Discuss:

- POLST (Provider Orders for Life Sustaining Treatment) of care as appropriate
- The role of palliative care and hospice with pain and suffering

Home and personal safety and independence:

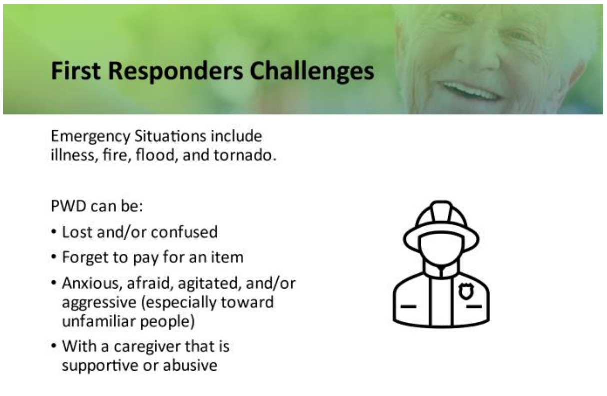
Healthcare professionals should refer patients to:

- A family caregiver advisor
- Emergency Home Response Program
- Alzheimer's Association Safe Return®

NOTE: Talk to client's physician for driving concerns.

Contact an occupational and/or physical therapist to address:

- fall risk
- recommendations for sensory/mobility aids
- home safety and accessibility modifications
- driving evaluation



First Responders Challenges

Emergency Situations include illness, fire, flood, and tornado.

PWD can be:

- Lost and/or confused
- Forget to pay for an item
- Anxious, afraid, agitated, and/or aggressive (especially toward unfamiliar people)
- With a caregiver that is supportive or abusive

First Responders Concerns

Disaster Response

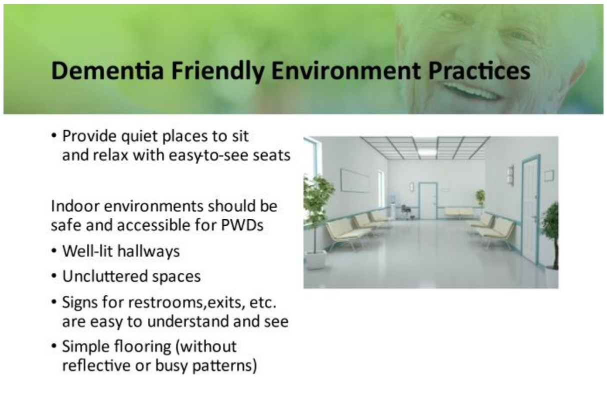
- Avoid physical force
- Remove PWD from danger
- Help PWD remain calm

Abuse and Neglect

- Injured? Go to hospital
- Not injured but unsafe? Go to safe location
- Safe? Refer to resources

Shoplifting

- Resolve with store manager
- Inform caregiver



Dementia Friendly Environment Practices

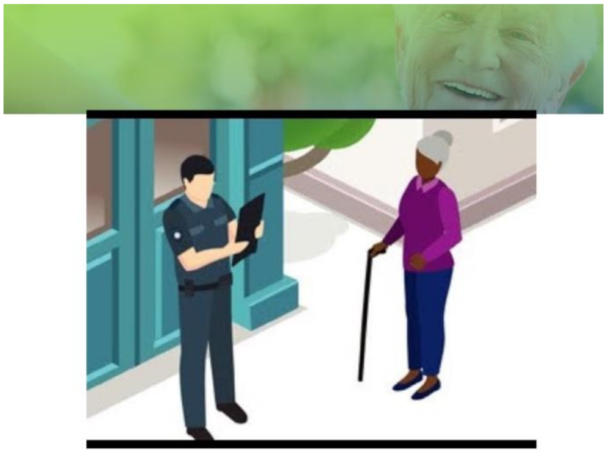
- Provide quiet places to sit and relax with easy-to-see seats

Indoor environments should be safe and accessible for PWDs

- Well-lit hallways
- Uncluttered spaces
- Signs for restrooms,exits, etc. are easy to understand and see
- Simple flooring (without reflective or busy patterns)

References APA

- AgeGuide Dementia Friendly For First Responders



Legal Sector

Regarding legal matters, the sector guide that I modeled the PowerPoint after had described the difficulties that not only PWD faced but also the difficulties of the lawyers and other legal representatives tasked to help them and their family (Dementia Friendly America 2020h). In order to be a successful legal representative within and to promote DFC initiatives, they should learn to identify financial abuse, learn about a PWD's legal challenges, and learn DFC practices specified for the legal field. By educating lawyers and other legal representatives on dementia needs and dementia-friendly initiatives, communities would be a step closer to creating a holistic DFC.

For signs of financial abuse, several examples were in the banks sector training section. Key issues that emerged were if there was a mismanagement of money by a third party, an unusual amount of money withdrawn, and a change in how a PWD used investments. Legal representatives should also be wary if it was hard to contact the PWD and if the PWD was being forcibly isolated. In short, if something seemed strange or off, legal representatives should do a follow-up meeting privately to make sure the PWD safe, even if and especially if the threat and treatment was by friends, family members, and/or their caregiver.

For legal challenges, the legal representative had to look out for the PWD's health and autonomy. With health, the legal representative should check-in with the PWD on the severity of their dementia. As with any other client with a disorder or other disability, law offices should create a standard procedure on how to work with PWDs. With autonomy, the PWD should tell the legal representative which caregiver, family member, or friend that they trusted to involve in legal discussions with them. In addition, the legal representative should have the ability to meet with the PWD privately, without having to worry about intrusive third parties that would make them reluctant to speak freely. By identifying and addressing legal challenges as they come along with the PWD, legal representatives can better comprehend that although the PWD has a cognitive disorder, their health and their autonomy are still possible for the PWD to maintain, with the help of genuine caretakers and definitely without avaricious caregivers.

For dementia-friendly legal practices, the PWD and caregiver have a myriad of paperwork to review and complete throughout the dementia care process. Before including the caregiver, legal representatives should make sure that the caregiver was not exploiting the PWD through fraud or neglect. Once the legal representative and PWD determine the caregiver's reliability, they have paperwork to prepare. This included advance directives, living trusts, and guardianship status. The legal representative should also examine abrupt changes in housing, such as a long-term care facility, and changes in the power of attorney. With the legal representative’s knowledge of dementia-friendly legal practices through the sector training, they could best help the PWD and their loved ones with the paperwork.

Giving legal representatives sector trainings on how to create a DFC through their sector was important because most were not specialized in dementia, much less dementia-friendly practices and DFC initiatives. Recognizing financial and other abuses allowed for legal representatives to better serve the PWD on their own terms or with the help of someone that they trusted. Approaching legal challenges in relation to the PWD was important to identify, so that the PWD could retain their autonomy as long as possible. Following dementia-friendly legal practices about abuse and law would provide lawyers tools to assist a PWD and the PWD's loved ones to complete required paperwork. Through sector trainings, legal representatives could best identify and act on suspicious behavior while prioritizing the PWD and promoting a DFC to spread these practices.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be non-legal staff or a Human Resources person. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Legal

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

Signs of Financial Abuse

Unusual changes in:
- Money usage by a third party
- Account withdrawals
- Investment style

Observing:
- Difficulty to contact client by you or others
- Isolation or intimidation of client from friends/family

Guidelines to Address Legal Challenges

- Encourage client to identify trustworthy family or friends
- Assess periodically PWD client's stage of dementia
- Meet with the client in private
- Involve caregivers in discussions as appropriate
- Follow standard practices for working with a client with a disability

Dementia Friendly Legal Practices

Look for client's values and wishes when seeing:
- Sudden changes (undue influence, fraud, neglect, or exploitation)
- Reviewing advance directives
- Sudden placement in long term care
- Power of attorney in effect
- The need for revocable living trusts
- The need for guardianship

Ways to Spread Dementia Friendly Principles

Partner with:
- Advocacy groups
- State agencies
- Regulators
- Agencies that follow and encourage dementia friendly practices

Connect with people to:
- Share learning experiences
- Spread best practices
- Promote dementia friendly principles within the field and community
- Become a Dementia Friend

- https://www.google.com/url?sa=i&url=https%3A%2F%2Fwww.shutterstock.com%2Fsearch%2Fsimple%2Bbalance%2Bscale&psig=AOvVaw14RS0VFAKI-BxBf4R9IFg8&ust=1616510277797000&source=images&cd=vfe&ved=0CAIQjRxqFwoTCKD2sZ6QxO8CFQAAAAAdAAAAABAD
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Community-based Services and Supports

Regarding community-based services and supports in the area, the sector guide I modeled the PowerPoint after had information on how to give resources to PWDs and their caregivers (Dementia Friendly America 2020c). It also had sections on recognizing symptoms of dementia and communication skills, but they repeated items from other sectors and gave little to no new information specific to support and services. With these resources, services and support should create local guides on “financial, legal, and care planning” in order to highlight the PWD’s needs and strengths (Dementia Friendly America 2020c, 2). All three topics were mentioned prior, and their examples could be found in previous sections. To highlight those, the community services and supports should host activities geared towards connecting PWDs with others and providing PWDs and their families assistance. Activities that connect people include storytelling, arts and music events, and health and wellness plans. Activities that assist PWDs include help around the home, such as house chores, meal delivery, and physical therapist recommendations. Through activities and resources, community-based services and support could work towards becoming a DFC partner.

Giving community-based services and support sector trainings on how to create a DFC through their sector was important because most were eager to further improve their community. They probably already planned activities for other initiatives in the area, so adding or incorporating DFC ones to their calendar and task list should be reasonable inclusions. These activities ranged from informal events, such as listening to music, to formal events, such as a visit from a physical therapist. If they followed the advice and looked for signs of dementia that they learned through sector trainings, these local services and supports can better reach PWDs and their families.

Dementia Friendly Communities Sector Training Guide: Community-based Services and Supports

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

Community-Based Provider Practice Tool

- Raise dementia awareness. Promote training across the community.
- http://www.actonalz.org/provider-practice-tools

Dementia Friendly Accomplishments
Transforming Communities Across Minnesota

ACT on Alzheimer's is a statewide, multi-dimensional collaboration seeking large-scale social change and building community capacity to help drive Minnesota's response to Alzheimer's disease.

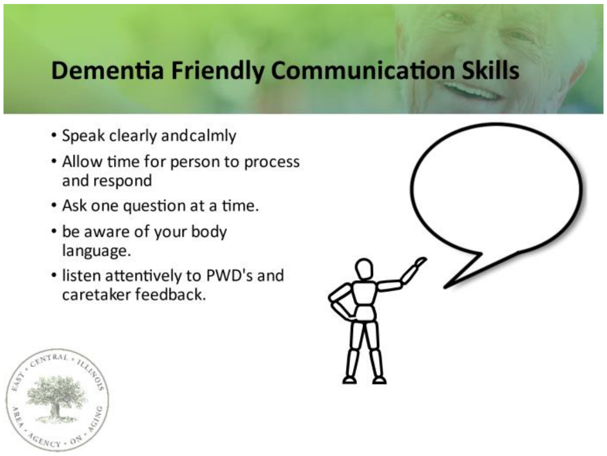
Implementing ACT Tools and Resources

Dementia Awareness resources help support community actions

400+ Health care providers and care coordinators trained on **Dementia Care Best Practices**

Practical webinars educate providers and community groups

150+ Participants learn, share and innovate at **Learning Summit** for ACT communities



Dementia Friendly Communication Skills

- Speak clearly and calmly
- Allow time for person to process and respond
- Ask one question at a time.
- be aware of your body language.
- listen attentively to PWD's and caretaker feedback.

Resources for People with Dementia and Care Partners

- Develop and distribute local resource guides to see what works best for or could benefit PWDs' situation
- Plan financial, legal, and care matters
- Engage and connect people by:
- Sharing positive qualities, creativity, and strengths
- Connecting across generations of PWD through art, music, or storytelling

Resources for People with Dementia and Care Partners

Connect PWDs with:
- Health and wellness activities

Utilize home-based services for:
- Chore services
- Home-delivered meals
- Home care

Address home / personal safety:
- Fall risk
- Sensory / mobility aids
- Driving
- Medication management
- Home modifications

Residential and Specialty Care

Regarding residential and specialty care facilities, the sector guide that I modeled the PowerPoint after focused its teachings on person-centered care (Dementia Friendly America 2020l). Residential and specialty care facilities were locations that care for and house older adults on a long-term basis (Dementia Friendly America 2020l, 1). Examples of some residential and specialty care facilities were “assisted and independent-living residences, home care, adult day services, [and] hospice” care (2020l, 1). As mentioned prior, person-centered care involves all parties focusing on, planning, and acting upon how to best help PWDs maintain personhood as they and their families age with dementia. Some of the sector training topics for residential and specialty care facilities were in other sections mentioned prior or later, such as health care, hospitals, or other care units involving direct treatment of the symptoms by doctors and nurses. Because of that, some material may be repeated. Topics that other sector training sections shared included person-centered care, positive behavioral health, and general environments. Topics that other section training sections do not share with this section include operational best practices, specialized person-centered care practices, and specialized environment practices. By focusing on person-centered care, all other variables that fall under the scope of dementia care could work towards becoming a DFC and conduct dementia-friendly practices.

For operational best practices, the care services should have inclusivity for all people involved in the dementia care process. First, leaders should make sure that they provide a work environment in which there is a low turnover rate and that creates a sense of community. For example, staff should make a fixed schedule, one that does not change too frequently to prevent confusion from PWDs and inconsistency with staff. However, this and other suggestions may not be possible, so everyone should try to be self-aware of this and be flexible. Once established, leaders should also make sure that all employees are trained in and are practicing person-centered care. An example of employees implementing what they learned is creating engaging events and spaces geared towards the betterment of the PWD, like memory cafés described previously. By placing PWDs first but also validating the work of the employees, residential and specialty care services can create a DFC in which PWD have support and the people supporting them also have support and so on.

For person-centered care practices, residential and specialty care services should be able to maintain, assess, and discuss the care of the PWD with them directly. Maintaining abilities and connections by focusing on the strengths of both allows for a feeling of both autonomy and community, such as encouraging a hobby. Assessing person-centered care involved care service employees getting to know the PWD’s likes and dislikes, their medical and personal history, their culture, and their religion. From the background, employees should compare and monitor these stories with current cognitive, physical, and sensory symptoms or behaviors. This was to identify inconsistencies that may indicate new health problems. Discussing person-centered care paperwork with the PWD was important before others were involved. Ideally, meetings should be done as frequently as possible before the condition gets worse. PWDs should have a say and know the trajectory of advance directives, end-of-life and hospice care, and funeral process. Through maintenance, assessment, and discussion of person-centered care and post-care, residential and specialty care service employees can better serve PWDs and can help with creating a DFC.

For specialized environment practices, they were different from general ones because the residential and specialty care services have a more concentrated population than other sectors of PWD. The general environmental and space making practices for PWD were in the trainings section and some of the other sector guide sections. What made this type of care service different was that it was primarily for older adults rather than the general population, like the hospital. Some environmental changes include hearing staff correspondence, seeing paths and signs, and providing activities that use all senses to experience it. Preventing PWDs from hearing staff correspondence was less about confidentiality and more about the comfort of the PWDs. Announcements and alarms can startle and upset PWDs due to the unexpected or overstimulating noise, so staff should use quieter or silent methods. Seeing clear paths and simple signs allowed minimization of indoor and outdoor wandering. Using all senses to experience activities, like gardening, was important to keep them alert in attention span and at peace with moderated stimuli. By providing a specialized environment where PWDs could use their senses, residential and specialty care services strengthened the DFC because they were an example of what dementia care should be, especially as part of the older adult and aging community.

Giving the residential and specialty care services sector trainings on how to create a DFC through their sector was important because most were also handling other medical issues from residents, like a physical disability or a psychological depression. Operational best practice laid the foundation on how leaders and employees run the care service. Person-centered care practices gave the tools to enrich PWD lives. Specialized environmental practices were the product of those two planning and learning stages. Through changes on an internal staff level and a groundwork with PWDs level, residential and specialty care services provided a welcoming environment to be with and to learn from in a DFC.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be Human Resources personnel or a head nurse. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Residential and Specialty Care

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

Types of Residential and Specialty Care

Residential and Specialty Care settings include:
- Long term care facilities
- Assisted and independent-living residences
- Home care
- Adult day services
- Hospice

Providing the highest quality care services requires a "whole person" or person-centered approach.

Operational Best Practices

- Have staff uphold person-centered philosophy
- Have a sense of community within and outside the organization
- Stabilize workforce and provide consistent staff assignments
- Improve quality of life with meaningful activities and engaging environments

General Person-Centered Care Practices

Get to know the client's:
- Life story
- Quality of life preferences
- Abilities
- Relationship with their caretakers and direct care staff

Minimize:
- Hospitalizations by looking for common infections and diseases
- Physical restraints and psychotropic medications

Specific Person-Centered Care Practices:
Person-centered comprehensive assessment and care plan

Maintain:

- Abilities and strengths that keep functional independence and individuality
- Connections with the community

Discuss PWD's plans and wishes for:

- Advance directives
- End of life and funeral preferences
- Palliative care and hospice

Assess

- Care goals, values, and preferences
- personal background and behavior
- communication abilities;
- cultural and spiritual preferences
- Abilities:
  - Cognitive (e.g., decisions)
  - Physical (e.g., pain)
  - Functional (e.g., hearing and vision)

Specific Person-Centered Care Practices
Maximize abilities, function and quality of life:

Address dementia and:

- Depression and co-existing medical conditions
- Lifestyle changes to reduce symptoms or progress
- Sensory issues (e.g. vision, hearing)
- Independence by doing activities **with** the PWD rather than **for** them

Support activities and routines that maintain and slow decline of brain health:

- Balanced diet and nutrition
- Physical health and exercise
- Cognitive activity
- Social engagement

Specific Person-Centered Care Practices
Engage in meaningful activities:

- Individualize approach by determining what is important to the PWD.

Leaders in the care community:

- model the value of engagement,
- provide education, and
- have resources available to help staff engage PWDs

Activities may involve:

- Movement/physical activity
- Mental stimulation
- Social interaction or solitude
- Intergenerational interaction
- Art/music
- Pets
- Spiritual connection
- Outdoors or nature
- Housekeeping or tasks
- Engaging the senses
- Comforting
- Other recreational interests.

Promote positive behavioral health:

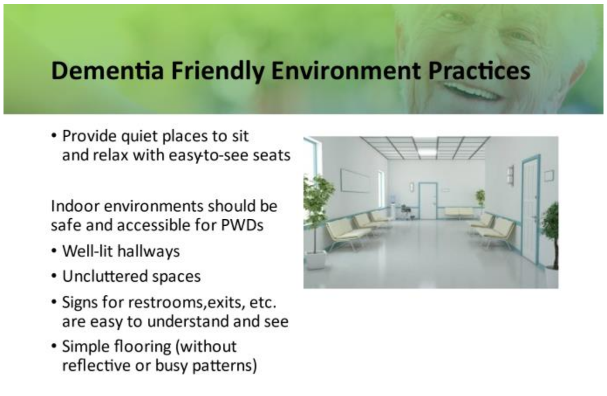
Identify and address:

- Behavior as a way to communicate:
- Unmet needs
- Reversible conditions
- Too much clutter or stimuli
- Care partner tactics on self-care, respite, and education

Use non-pharmacologic approaches to reduce symptoms:

- Focus on abilities rather than limitations
- Plan activities that engage interests and repetitive motion
- Plan tasks that match their capabilities
- Access training for care partners to improve communication, validation, and redirection
- Routine is essential

Use prescription drugs as a last resort.



Dementia Friendly Environment Practices

- Provide quiet places to sit and relax with easy-to-see seats

Indoor environments should be safe and accessible for PWDs

- Well-lit hallways
- Uncluttered spaces
- Signs for restrooms, exits, etc. are easy to understand and see
- Simple flooring (without reflective or busy patterns)

Hospital

Regarding hospitals, the sector guide that I modeled the PowerPoint after had information on how to interact with PWDs in that environment (Dementia Friendly America 2020g). When caring for PWD in a hospital setting, hospital employees should have training on specialized care, person-centered care, and adaptation of space. All three involved small and reasonable changes on normal hospital approaches and procedures.

For specialized care, hospital employees should first gather medical and medicinal history from the family, including observing what the PWD's normal mood is as a basis to compare to future reactionary behavior and planning for it. While discussing this, hospitals should have a list of local resources that the family could look at in regard to dementia, dementia care, and dementia-friendly practices. Included in that material should be discharge and post-discharge procedures and resources. The hospital staff should also be familiar with these dementia materials that they hand out. With the hospital logistics, hospital employees should increase comfort and safety check-ins in one-hour intervals to see if they need to adjust treatment, like medication intake, if not already on that frequency. By being active with the families on the PWD's care, hospital employees demonstrated how small accommodations and adjustments promoted DFC practices.

For person-centered care, this involved maintaining focus on the wants and needs of the PWD through the entire duration at the hospital in a way that maintained personhood. To start, hospitals should have a basic care plan for PWDs that doctors, nurses, and families can add and remove material from easily. Hospital volunteers should be aware of these plans and be required to become a dementia friend or do other dementia care training. Keeping person-centered care in mind, the hospital staff should collect information on the PWD's likes and dislikes, their preferred name, and their therapy style in relation to their senses (e.g., smell, sound, and touch). The hospital should also give PWDs access to comfort items and snacks that they like. Depending on the size and funding of the hospital, all of these may not be possible, so doing one or two of these suggestions does more than when it was none. With such small comforts, hospital employees provide a big difference in creating a DFC with their actions.

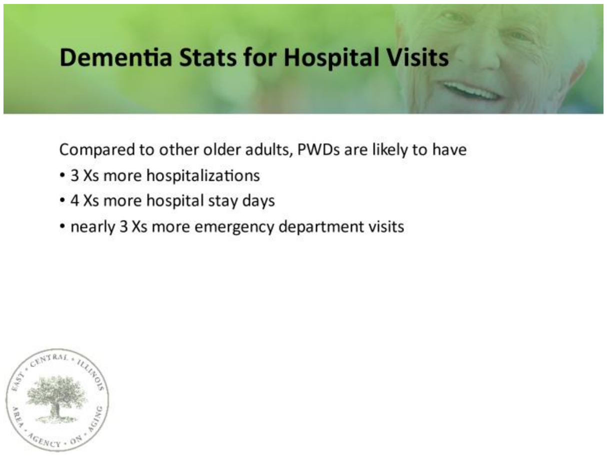
For adaptation of space, the hospital employees should be able to give PWDs clear indicators of what is done for what room. Starting with the PWD’s room, they should ideally have their own in a specialized dementia-friendly unit with employees who are familiar with dementia and dementia care practices. This prevents PWDs from upsetting one another or other hospital patients with noise or other conflicts. Other noise-free rooms aside from the PWD’s room should be a common area, a dining area, and an area for them to meet with their families. All of these rooms should be clearly labeled to prevent PWDs from falling, wandering, or getting lost. By adjusting rooms as needed, hospital staff will begin to see common quirks that PWDs share with one another or can extrapolate from these past experiences with another PWD, creating an awareness of the importance of working towards a DFC.

Giving hospital employees sector trainings on how to create a DFC through their sector is important because most are not specialized in dementia or treating PWDs. By giving the groundwork on dementia in regard to continuity of care, person-centered care, and adaptation of space. The adjustments to all of these categories tend to focus on noise reduction, knowledge gathering and sharing about dementia and dementia care, and preferred provisions for PWDs in the hospital. By having customizable and knowledgeable treatment for PWDs, hospital staff help promote DFCs by being a prominent sector that the rest of the community can learn from in their treatment of PWDs.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that are already Dementia Friends in this sector could present the sector training if Sheila could not, would be a head nurse or an activities coordinator. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities Sector Training Guide: Hospitals

Presented by: East Central Illinois Area Agency on Aging (ECIAAA)

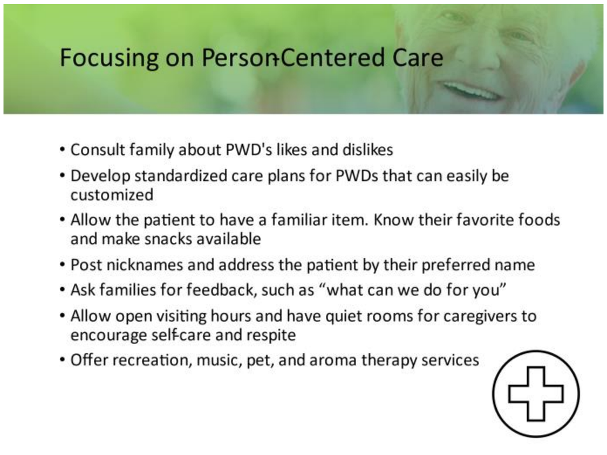


Dementia Stats for Hospital Visits

Compared to other older adults, PWDs are likely to have
- 3 Xs more hospitalizations
- 4 Xs more hospital stay days
- nearly 3 Xs more emergency department visits

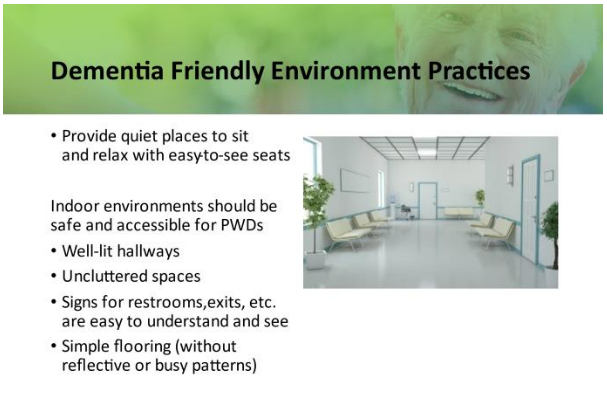
Practical Steps for Improving Care Include:

- Hourly comfort and safety rounds
- Keep patient's staff consistent
- Know baseline behavior from family and caregiver report.
- Develop a plan to recognize, assess and intervene with agitated patient
- Continually assess medications and educate families on medication use. Encourage questions, especially regarding discharge.
- Provide Alzheimer's disease information and a resource list to families
- Communicate and coordinate care with family and post-discharge providers
- Provide dementia education and training for all staff and volunteers. Find training resources at: https://www.dfamerica.org/provider-tools



Focusing on Person-Centered Care

- Consult family about PWD's likes and dislikes
- Develop standardized care plans for PWDs that can easily be customized
- Allow the patient to have a familiar item. Know their favorite foods and make snacks available
- Post nicknames and address the patient by their preferred name
- Ask families for feedback, such as "what can we do for you"
- Allow open visiting hours and have quiet rooms for caregivers to encourage self-care and respite
- Offer recreation, music, pet, and aroma therapy services



Dementia Friendly Environment Practices

- Provide quiet places to sit and relax with easy-to-see seats

Indoor environments should be safe and accessible for PWDs
- Well-lit hallways
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- Signs for restrooms, exits, etc. are easy to understand and see
- Simple flooring (without reflective or busy patterns)

Transportation

Regarding rural and urban transportation, there was not a specific sector guide to use as a model (Dementia Friendly America 2020j). However, information was in other sector guides and other material. To foster a DFC, the transportation sector could make plans to accommodate the pavements, automobiles, and logistics of public transportation.

For pavement, the transportation sector should consider changes in not only the roads but other created pathways. All of this is assuming that they may not have funding, permissions, or manpower to do all of these changes and could start with just doing one. Pavement includes roads for cars, sidewalks for walking and biking, crosswalks with clear signs and sounds, and other types of streets in neighborhoods, such as cul-de-sacs. Some of the changes that all of these types of pavements can make are better lighting in the evening, increased placement of "wide, smooth, flat/low slope[s]" in elevated areas, and more efforts to keep pavements litter-free (Dementia Friendly America 2020j, 2). In order to do this, the transportation sector would need to collaborate with DFC leaders and city developers. The areas should also have frequent maintenance and protection, such as functioning crosswalks and clearly separated sidewalks from roads. With pavements affecting driving, biking, walking, and other modes of transportation, it is important for creating a DFC to have these pavements in consideration.

For automobiles used for public transportation, the transportation sector should keep DFCs and PWDs in consideration because their proposed accommodations could improve access to other group initiatives as well. Public transportation and other means of driving should be "consistent, reliable, accessible, and affordable" for not just a DFC but an age-friendly community, a disability-accessible community, and other initiatives (Dementia Friendly America 2020j, 3). In the machinery itself, PWDs should be able to move around safely and open doors with little struggle. The transportation sector leaders should also have training for drivers on

DFCs through sector guides. Other automobiles include public services like Medicare vehicles and private services like taxies are also other means of transportation that should still follow the guidelines listed above. In order for the roads and their vehicles to become dementia-friendly, the transportation sector must work on the logistics of getting these changes implemented.

For logistics, the transportation leaders need to cooperate with other community members to propose, fund, and implement changes in their sector. Proposals include working with land developers and rural communities to determine what to do with current or future pavement. Funding involves conducting an awareness program, both for alterations to public transport and alternatives to automobiles, increasing the quality of the former and decreasing the barriers to mobility throughout the community for the latter. Implementing requires outreach to share and demonstrate these changes as well as training employees on DFC and on other new materials. This quick outline does not come close to describing the steps into which the transportation sector can become more dementia-friendly, but once changes start to happen, there will be more unity in the DFC because the literal pavements connecting everyone to each other have adapted to the needs of PWDs, their families, and other initiatives that had similar needs.

Giving the transportation sector trainings on how to create a DFC through their sector is important because most encounter PWDs but do not register it. Some bus drivers probably think the PWD is a person without money trying to hold up the line. Some crossing guards may see a PWD as an inconsiderate person who does not pay attention to the do not cross signal. Some bystanders may see a PWD slowly climb up the stairs and feel pity for them but are unsure how to help, if they want to help at all. All these and other scenarios regarding PWDs inconveniencing people need compassion and consideration. With more work on pavements, public transportation, and logistics, the sector can incorporate that compassion and consideration into productive action.

As for the distribution of this training, someone from ECIAAA or another person approved by ECIAAA could conduct the sector training. Potential leaders that could present the sector training if Sheila could not would be Human Resources. Through this leadership delegation, ECIAAA and their partners within the different sectors could present sector trainings more frequently.

Dementia Friendly Communities
Sector Training Guide: Transportation

Presented by: East Central Illinois
Area Agency on Aging (ECIAAA)

Mobility planning and coordination:

- Develop policy that fosters complete streets, pedestrian safety and ease, and rural access
- Recognize increased dependence on automobile due to limited physical, sensory, and cognitive function, which makes using public transportation independently more difficult.
- Plan for when a PWD can no longer drive to reduce isolation and dependence in the future.

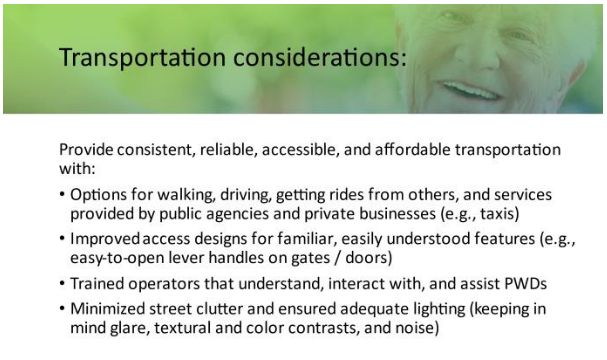
Mobility planning and coordination, continued:

Promote easy-to-navigate public spaces that incorporate universal design features:

- Signs
  - Visible
  - Easy-to-read
  - Contains schedule
- Trails and sidewalks
  - Wide
  - Smooth
  - Flat/low slope
  - Non-slip
  - Well lit in evening

Design dementia friendly:

- Safe roads and walking/bicycling environments for drivers and pedestrians
- Walking/cycling paths are protected from heavy traffic
- Crosswalks have audible cues and appropriate timing



Transportation considerations:

Provide consistent, reliable, accessible, and affordable transportation with:

- Options for walking, driving, getting rides from others, and services provided by public agencies and private businesses (e.g., taxis)
- Improved access designs for familiar, easily understood features (e.g., easy-to-open lever handles on gates / doors)
- Trained operators that understand, interact with, and assist PWDs
- Minimized street clutter and ensured adequate lighting (keeping in mind glare, textural and color contrasts, and noise)


Dementia Friends America Video

Coursework Connections to Capstone: The Real-World Application

For the Applied Community and Economic Development (ACED) program that gave me this opportunity to be a Stevenson Fellow at ECIAAA, they required that the first year was course-intensive and that the second year was the professional practice. The coursework that the ACED Fellows did was created in a way that prepared us for real-world applications of community development, such as our work during our professional practice. When thinking about the first- and second-years' experiences, two community development concepts came into mind in regards to this capstone project of DFC Sector Trainings: 1) bonding and bridging social capital and 2) the multi-paradigm community intervention approaches. This section will demonstrate the successful applications and parallel connections that the first year's courses had with the second year's professional practice.

Regarding bonding and bridging social capital, both types were apparent throughout the DFC process and the Sector Trainings. Bonding social capital was when people with similarities actively connected with each other, such as Asians grouping with other Asians and middle-class people grouping with others in the same income bracket (Phillips and Pittman 2009, 6). Bridging social capital was when people with differences actively connected with each other, such as

Asians grouping with Latinos and Christians connecting with Muslims (2009, 6). In the case of ECIAAA's DFC initiative, we were trying to bridge social capital between different sectors of the community. Although the common bond was wanting to help create a dementia-friendly community, bridging different sectors of the community with one another in committees was a vital step in the DFA Toolkit. The committees were scheduled to occur in the middle portion of the Toolkit.

ECIAAA started, while I was there and continued when I completed my term, to gather stakeholders from these different sectors to establish community leaders and other key members. By bridging the different sectors with ECIAAA and the plan to create a DFC, the designated community for the DFC should have committee-wide support and acknowledgement. This is because all the sectors were trained on the basics of dementia and PWDs as well as dementia-related material specialized for their sector. Although bonding and bridging were never the labels used to describe the DFC process, the teachings of our Community Development course gave us the tools to identify it in real-world applications and settings.

Regarding community intervention approaches, there were three aspects of the capstone project experience that resembled these approaches. The approaches were: 1) social planning, 2) community organizing, and 3) community development. Social planning involved defining and addressing social challenges through the use of research, professionals, and other experts (Sites et al 2012, 39). Community organizing involved bringing together marginalized groups with a common goal of challenging majority groups for equal "resources, recognition, or broader social change" (2012, 40). Community development involved keeping "key internal assets (people, relationships, associations, etc.)" at the forefront of efforts to lead and benefit these members

(2012, 41). All three had some connection to DFCs from DFA and/or ECIAAA's journey to become a DFC.

For social planning, DFA created the DFC Toolkit through trial and error of developers in the dementia field (Sites et al 2012 38-47). For community organizing, ECIAAA and other older adult leaders challenged different sectors of their community to adopt practices for and acknowledge the needs of the marginalized group of PWDs. For community development, the Toolkit idealized having all stakeholders involved, including PWDs and their caretakers. Combined, these community interventions created an environment where dementia and PWDs are at the core of the vision, plans, and actions of community and sector leaders. Despite the Toolkit and ECIAAA not using this vocabulary for community intervention, their plans still followed the concepts.

Anthropological Reflection: The Lesson

Throughout the learning process of dementia and DFCs, one of the key anthropological methods I used was immersion. For immersion, I participated in different trainings, webinars, committee meetings, and other events related to dementia and DFCs. From these people, I heard from staff directly working with PWDs in a care setting to others who studied dementia through scientific research. One of the key ways to immerse myself further that I could not do was participant observation. The importance of immersion and participant observation here runs parallel with anthropologist Clifford Geertz and the Balinese cockfights. During his study with his wife, they were treated coldly by locals (Geertz 1972). It was only after they ran away from the police with others watching an illegal cockfight that people opened up to them. As outsiders, they could have explained they were researchers, but they were able to immerse themselves into the community with this solidarity. Although my experience with ECIAAA is not as suspenseful as their circumstance, the importance of immersion, or rather the lack thereof in my case, was a vital point that fell short in my capstone and professional practice experience.

Because of COVID-19 restrictions, all care facilities were closed to almost all visitors. This included family, friends, and other loved one in terms of personal visits. It also included other agencies who normally provided services, such as a book mobile from the library, a beautician for hair and foot care, and other events that would either bring outsiders into the facility or bring the PWDs and other older adults outside. My closest observations were when there was a Q&A panel with PWDs and their families during my training and when I volunteered for Mind&Melody to play music for older adults with cognitive impairments during my undergraduate years.

On an anthropological level, this limited immersion made it clear that there was only so much you could learn while behind a desk. I learned from and even had planning discussions about DFCs from experts in the field. However, outside of my personal experience, I did not visit a residential and specialty care service or other care facility. A nurse taking the training with me assured me that there were still bright sides to working with PWDs. For the first few months, I broke some but not all misconceptions about dementia. I probably still have some now. With the nurse’s personal stories of the laughs, she shared with patients and several others echoing her sentiment, I could see that I was missing a personal connection. Establishing rapport with professionals could only go so far.

Moving forward, I will keep this limitation that I had with immersion in mind. As an Applied Community and Economic Development (ACED) Fellow for the Stevenson Center, my experiences revolved around community service. To get admission to the group, I had to verify that I was an AmeriCorps VISTA for two years. To stay in the Fellowship, I had to take classes on learning how to work with community development. With my experience at ECIAAA while learning about DFCs, I found further evidence that people affected by choices another party makes should have a say in the matter as a stakeholder. For DFCs, this included PWDs. For my AmeriCorps VISTA experience with the immigration law, this included the immigrants themselves. For future agencies I work with, it will be the people that they serve. Through my experience with my capstone project, it further reinforced to me the importance of immersion and establishing rapport, not just with "experts" but also with stakeholders, such as the people that research focuses on and others impacted.

Conclusion: The End

In all, dementia-friendly communities were more intricately complex and immensely informative than I could document during my year with ECIAAA. Before learning more in-depth about dementia and DFCs, my supervisor had me take the time to know the aging network AAA, the agency ECIAAA, and the RSI committees. During my education on dementia and DFCs, I listened to academics and professionals share their findings, doctors and nurses share their stories, and PWDs and their families share their lived experiences. After learning about dementia and DFCs, I took what I learned and created sector trainings catered to different parts of the community in order to share information about dementia and about creating DFCs. This capstone project was important and vital to ECIAAA because although there were sector guides and other material already in existence, there were few sources that were in a presentation format. In particular, my supervisor and coworker wanted presentations that could be done in thirty minutes or less, which some of the few presentations lacked. So, I helped make that possible. The sector trainings would hopefully help with Champaign County and Vermillion County’s progress towards becoming a DFC, which looked promising by the time I completed my practicum with ECIAAA. What I learned before, during, and after being introduced to the basics of dementia and DFCs will leave an impression on me, and I hope this capstone leaves an impression on you.

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Appendices

A. Abbreviation and Terminology

Appendix A: Abbreviations and Terminology

- AAA
    - Area Agency on Aging
- ACED
    - Applied Community and Economic Development
- ACL
    - Administration on Community Living
- Alz
    - Shorthand; see Alzheimer's entry
- Alzheimer's
    - A type of dementia often used interchangeably with dementia itself
- AOA
    - Administration on Aging
- Dementia
    - A cognitive impairment that interferes with living an independent life
- Dementia Champions
    - People trained by RUSH Medical Center of Chicago to conduct Dementia Friends presentations in order to recruit more Dementia Friends
- DF
    - Dementia Friends
- DFA
    - Dementia Friends America
- DFC
    - Dementia-Friendly Community
- ECIAAA
    - East Central Illinois Area Agency on Aging
- IDoA
    - Illinois Department on Aging
- ISU
    - Illinois State University
- PWD
    - Person(s)/People with Dementia
- RSI
    - Reducing Social Isolation
- SI
    - Social Isolation