**PROJECT NARRATIVE**

**A. Background**

Alzheimer’s disease, a neurodegenerative disorder, is the sixth-leading cause of death in the United States. Alzheimer’s disease is also among the leading causes of disability in the country. The Alzheimer’s Association has reported that 5.7 million Americans are currently living with Alzheimer’s disease. The Centers for Disease Control and Prevention (CDC) has reported that the burden of Alzheimer’s disease and related dementias (ADRD) will double from 1.6% in 2014 to 3.3% in 2060. According to the CDC report, Hispanics and African Americans will carry a disproportionate burden of ADRD, respectively accounting for 3.2 million and 2.2 million of the total infections in 2060. Although Alzheimer’s disease is prevalent among individuals aged 65 years and older, 200,000 Americans below 65 years have early-onset of dementia.

## The Need

Kansas was the last state in the union to develop a state dementia plan. However, this in no way identifies us to the level of commitment given to ensure Kansas individuals with Alzheimer's Disease and Related Dementias (ADRD) are a priority in our communities. Kansas is primarily of rural population. According to U.S. Census, the total population in Kansas is around 2.9 million; approximately 30 percent reside in urban areas and 70% reside in rural communities.

Both communities play a critical role in supporting persons with ADRD and their caregivers.

There is growing evidence that effective management of ADRD requires a team approach and support of a community. One of the essential needs identified by the Kansas State Dementia Plan is to develop content for a statewide education campaign to address a wide range of issues and audiences and ensure that the public awareness campaign addresses the diverse ethnic, cultural, linguistic, and literacy differences of Kansans. Kansas is no exception with 54,000 diagnosed citizens with Alzheimer's and as our population ages, we will need a consistent robust education and training MFCP for caregivers and the entire community with which ADRD individuals live.

The disease also imposes a significant cost burden at both the state and individual levels. Notably, Kansas spent $441 million Medicaid allocation on persons with Alzheimer’s disease in 2019. The Medicaid costs will increase by 21.7% to $537 in 2025. The growing burden of Alzheimer’s disease influence the creation of the Kansas Alzheimer’s Disease Task Force under Executive Order No. 19-08 that Governor Laura Kelly signed in May 2019. The Task Force has developed the 2020 Kansas Alzheimer’s Disease Plan.

## The Solution

Public education is one of the three core principles specified in the Healthy Brain Initiative (HBI) Road Map. Education is necessary to shift attitudes to normalized discussions about cognitive health, including conversations about early detection of memory loss and reduction of risk.

Persons living with ADRD believe that their lives would improve if their community had an in- depth understanding of what it is like to have dementia and how to help. Persons like Gary-this is **Gary’s Story**.

Gary, a 73-year-old Kansas man, was referred to a neurologist by his primary care doctor for symptoms of memory loss. Gary’s family reported that he had begun to have significant changes over the past year. He had stopped bowling or participating in antique tractor pulls, which he had enjoyed both for decades. After follow-up tests Gary was diagnosed with Alzheimer’s disease in March of 2016.

The final episode, which caused Gary to fully isolate himself at home, was going for his routine lunch stop. When Gary walked in, the staff greeted him and said, “Go ahead Gary and sit in your usual place”. Gary didn’t remember where it was, so he sat at the first table. Gary’s waitress heckled him about sitting at the large table. Next, she asked if he wanted his usual lunch and all Gary could do was stare at the menu. He was confused, he could not remember what his usual lunch was, highly embarrassed, Gary got up and walked away. Gary never went into public again. Within a few months of these episodes Gary began to rapidly decline in his health and memory. One of the hardest parts for the family was not being able to help Gary understand that he was ***“living”*** with Alzheimer’s, not ***“dying”*** with it. But it was difficult to convince him when the community he lived in lacked the understanding of Alzheimer’s. Gary’s community appeared horrified by the stigma of Alzheimer’s and was absent of knowledge to help Gary live actively among them.

The best way of improving community knowledge to support ADRD is through the delivery of education and training **directly to the community**. The decision to target Kansans in their community is strategic since many of them have limited access or skills related to technology use. Accordingly, the Garden City Community College (GCCC) has developed a unique program to build memory friendly communities in Kansas. The **Memory Friendly Communities Program** (MFCP) will inform the public about cognitive decline, as well as empower individuals with ADRD and their caregivers. The overall goal of the MFCP is to make GCCC the Public Health Center of Excellence (PHCOE) for Dementia Caregiving in Kansas.

# Approach

## Purpose

The purpose of the MFCP is to establish a state-based framework for implementing the Healthy Brain Initiative Road Map on Dementia Caregiving. The MFCP will ensure that state, local partners, and tribal public health agencies can strengthen its caregiving capacity and leverage it to enhance outcomes for patients with ADRD and their families.

The MFCP will ensure Kansas is a best practice for **Dementia Caregiving** by educating and training a diverse range of population groups across the rural communities. Caregivers, first responders, key community support systems, and in-home health care personnel will be educated, given tools and support to identify dementia-related behaviors and have tools to cope with their patients, as well be confident in their abilities to inform other community members.

## Outcomes

The best way to improve community knowledge to support ADRD citizens is to deliver education directly to the community. With many Kansans lacking access or skills to technology use, it is important to reach out to them in their community. Garden City Community College has developed a unique program to build memory friendly communities in Kansas with our mobile classroom and simulation lab. This uniquely developed program will travel to Kansas communities with professionally trained facilitators to provide the certified training required for Alzheimer's families to:

* + train health care workers, public safety personnel, and community members to understand the special needs of Alzheimer's families, patients, and caregivers to be socially active, engaged in their community, and promote healthy brain living.

The three focus areas to deliver on the activities:

1. *Mobile Classroom and Simulation Lab (W3, P1, E7, E1, M3)*
2. *Public Relations and Communications (E3, P3, P1, W3)*
3. *Collaboration and Partnerships*, *(W4, W1,E3, E1)*

are all based on the HBI Road Map 2018-2023.

## Mobile Classroom and Simulation Lab Short/Mid/Long Term Outcomes Model

The **Memory Friendly Communities Program** combines mobile classrooms and simulation labs to ensure rural Kansas through the delivery of consistent training tools will improve access to and the use of evidence-informed interventions and supports for people with dementia and their caregivers that will enhance their health, well-being, and independence. (E7)

The Mobile Classroom that Garden City Community College (GCCC) uses for educational and health purposes will enable the MFCP to reach all of Kansas and more important, provide outreach to the rural, under-served, and minority communities unlike any other method of delivery. The MFCP will give GCCC the and the Garden City Community College Nursing and Allied Health Department, the Public Health Center of Excellence designation for Dementia Caregiving in the state of Kansas.

A lack of public awareness is one of the challenges that has stymied the achievement of national and state goals on dementia-related behavior and Alzheimer’s disease. But the following **Outcomes** will make great strides in making Kansas a Memory Friendly state.

* Increased public awareness will play a vital role for caregivers supporting their patients and family members with dementia.
* Increasing access to effective interventions to protect brain health and support caregivers in their ability to respond to dementia-related behaviors.
* Reaching minority and under-served rural populations for the first time will be a “game-changer” in improving a community response, understanding and inclusiveness of Alzheimer patients and their caregivers
* Simulation labs can enhance understanding for the community, family members and caregivers like no other tool; “walk a mile in my shoes” with sensory equipment is incredibly powerful
* Warning Signs and Early Detection education will greatly reduce hospital visits and potential deaths, as well as giving caregivers confidence about their caregiving ability
* Communities learning to “decode” dementia-related behavioral signs and recognizing geriatric skin conditions will empower many people and add to their understanding of their fellow community members