Landscape Report

Alzheimer's Disease & Related Dementia Care in Iowa

IDPH
IOWA Department of PUBLIC HEALTH

Acknowledgment

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Introduction

The Iowa Department of Public Health (IDPH) recently was awarded a capacity building cooperative agreement (NU58DP006921) from the Centers for Disease Control and Prevention (CDC) to inform and develop public health infrastructure to improve and expand efforts that address the challenges presented by Alzheimer's disease and related dementias (ADRD). In its initial work in 2021 under this cooperative agreement, the IDPH realized the need to survey the Iowa landscape believing this work is critical to informing and then developing an efficient and effective approach to implement the CDC's *Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act*, Public Law 115-406 in Iowa. This assessment defines the current demand for dementia care by accounting for the prevalence of Iowans with ADRD and their related use of health and supportive services including information and education about ADRD; and documents programs and services dedicated to persons with ADRD and estimates access and use. Finally, the assessment considered the importance of public education efforts as a first step, reviewed current public education efforts in Iowa, and looked to other states that have already taken steps toward improving and expanding public education.

IDPH realized the need to survey the Iowa landscape to inform and develop an efficient and effective approach to implement the CDC's initiative on Alzheimer's and Dementia.

Alzheimer's Disease in Iowa

The prevalence of ADRD in Iowa was estimated with low, medium, and high series projections. The first approach is a calculation based on neurological autopsy studies with confirmed diagnosis of ADRD. The others are based on clinical and observational survey studies of persons who presented symptoms pertaining to the diagnosis of ADRD and mild cognitive impairment. These rates were then matched to US Census estimates specific to Iowans over the age of 65 who were living at home in the community as well as those within residential facilities. **Table 1** (on next page) shows three epidemiological estimates for ADRD burden in Iowa that vary based on different research methodologies. The methods for each estimate are explained in depth in the following paragraphs.

Low estimate (Brookmeyer et al.)

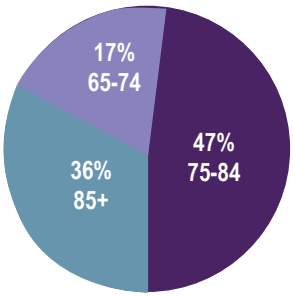
The low estimate for ADRD disease burden is based on research conducted by Ron Brookmeyer at Johns Hopkins University Department of Biostatistics in 2006. This stochastic, multi-state model states that

> *"...the prevalence rates at ages 65, 75 and 85 were 0.9%, 4.2% and 14.7% respectively". When applied to United States Census data about the older than 65 population in Iowa, this indicates that 20,601 people have diagnosed or undiagnosed ADRD in 2020.*

There are 70,397 Iowans living with subjective cognitive decline in Iowa in 2020.

Medium estimate (Chicago Health and Aging Project projections)

The medium series estimate is derived from the Chicago Health and Aging Project, a longitudinal population study (n≥10,000) with successive age cohorts of chronic health problems and risk factors for Alzheimer's disease conducted at Rush University in Chicago. This study included direct clinical evaluation for Alzheimer's disease in a random sample of all participants. The proportional distribution of Alzheimer's disease among different age cohorts was found to be 17% for ages 65 to 74, 47% of those aged 75 to 84, and 36% of those older than 85. When statistically adjusted for demographics and applied to the population of Iowa, there are 66,000 people living with diagnosed or undiagnosed Alzheimer's disease in 2020. The Alzheimer's Association uses the Chicago Health and Aging Project estimations for Alzheimer's disease in their 2020 Facts and Figures report.



High estimate (Behavioral Risk Factor Surveillance System projections)

The Behavioral Risk Factor Surveillance System (BRFSS) is a federal program for which state-based research teams conduct telephone surveys of non-institutionalized adults over 18 years of age to study a variety of health outcomes. The BRFSS Subjective Cognitive Decline Module estimates the number of adults who experienced cognitive decline which is the first symptom of ADRD and the point at which many people are diagnosed or first treated. The most recent BRFSS Cognitive Decline Module in 2015 found that 6.6% of Iowans age 65 to 75 have subjective cognitive decline followed by 10.6% of those aged 75 to 79 and 16.7% of those above 80. This indicates that there are 70,397 Iowans living with subjective cognitive decline in Iowa in 2020.

2015 BRFSS Cognitive Decline Module

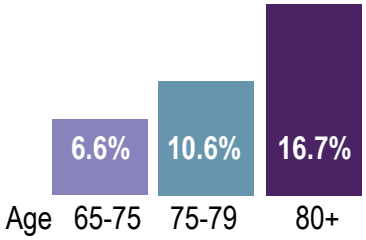


Table 1, Iowa ADRD Disease Estimates by County

County	Total 65+ Population	Low	Medium	High
State of Iowa	525,522	20,601	66,000	70,397
Adair	1,566	70	197	223
Adams	836	33	105	127
Allamakee	3,076	125	386	394
Appanoose	2,827	117	355	362
Audubon	1,354	63	170	196
Benton	4,631	182	582	645
Black Hawk	21,138	806	2655	2943
Boone	4,665	180	586	629
Bremer	4,866	189	611	709
Buchanan	3,769	145	473	489
Buena Vista	3,027	139	380	359
Butler	3,268	132	410	437
Calhoun	2,222	100	279	296
Carroll	4,000	192	502	520
Cass	2,954	129	371	406
Cedar	3,553	144	446	500
Cerro Gordo	9,043	380	1136	1187
Cherokee	2,666	130	335	328
Chickasaw	2,420	91	304	358
Clarke	1,671	62	210	259
Clay	3,329	149	418	434
Clayton	4,045	163	508	554
Clinton	9,057	361	1137	1240
Crawford	2,900	112	364	406
Dallas	10,357	381	1301	1356
Davis	1,555	64	195	210
Decatur	1,567	67	197	213
Delaware	3,276	138	411	398
Des Moines	7,981	316	1002	1067
Dickinson	4,374	170	549	575
Dubuque	16,778	662	2107	2335
Emmet	1,937	82	243	271
Fayette	4,159	172	522	576
Floyd	3,428	147	431	464
Franklin	2,109	83	265	305
Fremont	1,547	60	194	204
Greene	1,996	86	251	266
Grundy	2,519	103	316	340
Guthrie	2,358	87	296	350
Hamilton	3,024	142	380	365
Hancock	2,358	105	296	306
Hardin	3,634	164	456	482
Harrison	2,736	104	344	391
Henry	3,676	148	462	493
Howard	1,866	84	234	235
Humboldt	1,987	85	250	275
Ida	1,511	63	190	211
Iowa	2,984	122	375	460
Jackson	3,957	157	497	503
Jasper	6,989	259	878	1028

County	Total 65+ Population	Low	Medium	High
State of Iowa	525,522	20,601	66,000	70,397
Jefferson	3,915	126	492	468
Johnson	16,810	596	2111	2055
Jones	4,144	175	520	544
Keokuk	2,194	90	276	319
Kossuth	3,456	156	434	481
Lee	6,805	249	855	898
Linn	34,771	1,330	4367	4580
Louisa	2,049	76	257	300
Lucas	1,836	72	231	278
Lyon	2,103	96	264	281
Madison	2,735	101	343	346
Mahaska	4,005	163	503	517
Marion	5,805	231	729	762
Marshall	7,069	274	888	1009
Mills	2,711	97	340	326
Mitchell	2,306	107	290	319
Monona	2,125	89	267	316
Monroe	1,533	58	193	204
Montgomery	2,100	82	264	320
Muscatine	6,908	264	868	885
O'Brien	2,836	142	356	342
Osceola	1,269	64	159	166
Page	3,305	138	415	433
Palo Alto	1,938	90	243	254
Plymouth	4,531	207	569	563
Pocahontas	1,544	65	194	233
Polk	61,222	2,142	7689	8186
Pottawattamie	15,838	601	1989	2045
Poweshiek	3,715	148	467	527
Ringgold	1,192	56	150	146
Sac	2,270	96	285	298
Scott	27,192	1,008	3415	3566
Shelby	2,632	121	331	355
Sioux	5,301	225	666	755
Story	11,437	446	1436	1491
Tama	3,324	139	417	464
Taylor	1,355	57	170	175
Union	2,475	104	311	332
Van Buren	1,582	55	199	209
Wapello	6,100	230	766	863
Warren	7,781	271	977	1044
Washington	4,141	180	520	541
Wayne	1,395	58	175	202
Webster	6,587	268	827	859
Winnebago	2,197	89	276	307
Winneshiek	4,057	169	510	567
Woodbury	15,071	559	1893	2044
Worth	1,503	61	189	188
Wright	2,806	132	352	353

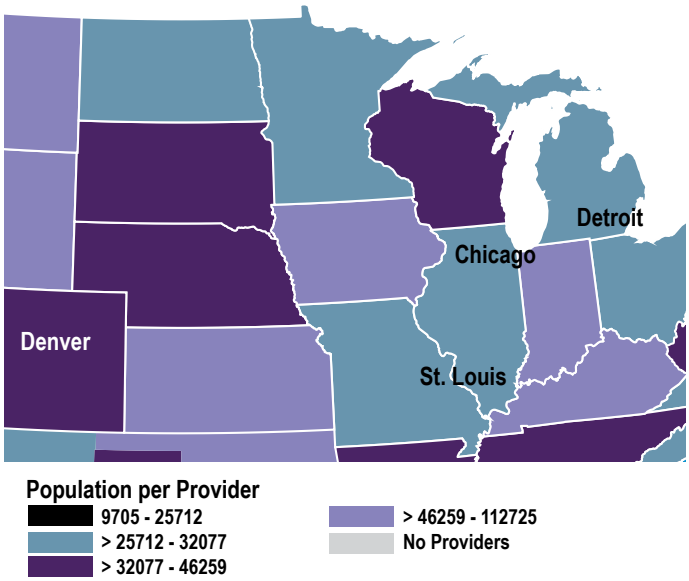
Evidence-based Services & Supports

People living with ADRD, along with their caregivers and family, can benefit from accessing programs and services tailored to identify dementia and implement plans of care that address the most problematic symptoms. It is well-established that the majority of people with ADRD would prefer to stay in their homes and chosen communities for as long as possible before transitioning to residential facilities. This notion is affirmed in the Iowa State Plan on Aging, which highlights how the state is committed to allowing Iowans to remain in their homes as long as possible by providing access to home-based and community services (Zabalegui et al 2014; Callahan et al 2017). As such, the accounting of such program's services most relevant to persons with ADRD will follow the clinical trajectory of a person who endures dementia anywhere between two and 20 years after being identified. By examining the prevalence of ADRD relative to provision of programs and services, gaps were identified and recommendations were made for how Iowa's public health roadmap can best navigate this landscape.

Physician Workforce

Primary care, family physicians and other qualified health care providers often offer the first opportunity to formally identify a person who may be experiencing forgetfulness, mild cognitive decline or ADRD. These initial evaluations can be conducted in less than 15 minutes and can provide sufficient reason for referral for more intensive, evidence-based diagnostic assessment. However, many of these front-line health care workers have neither the training nor incentives to do this. The American Association of Medical Colleges produces a yearly State Physician Workforce Report that accounts for the number of physicians across various specialties in each state. In 2019, there were 1,196 people for each primary care-family medicine physician in Iowa, 62% of these primary care physicians are located in urban areas and 38% are in rural areas. In addition, neurologists and geriatricians are most likely to be qualified to diagnose ADRD and develop individual treatment plans. There are 96 neurologists in Iowa, which equates to 5,356 older Iowans per neurologist. There are 33 geriatricians in Iowa which equals 15,582 older Iowans per geriatrician. Figure 1 displays the American Medical Association Health Workforce Mapper, which demonstrates that there are fewer neurologists and geriatricians in Iowa compared to surrounding states including Michigan, Minnesota, Illinois, Missouri, Nebraska, and South Dakota.

Figure 1, American Medical Association Health Workforce Mapper Population of Geriatric and Neurology Physicians



Iowans who are over the age of 65 and enrolled in Medicare have the opportunity to utilize Annual Wellness Visits and be formally evaluated for cognitive impairment. The Medicare Annual Wellness Visit is covered under Medicare Part B insurance and is completely free to all beneficiaries, even if the beneficiary's yearly deductible has not yet been met. It is estimated that fewer than one in every four Iowa Medicare beneficiaries completed a wellness visit in the past year in Iowa even though there is no financial co-payment (Holland, 2019). **Improving and expanding awareness of this service could have a significant impact on the early diagnosis of cognitive impairment associated with ADRD.**

less than 1 in 4
Medicare beneficiaries completed a wellness visit

Memory Clinics

A patient who is evaluated by a primary care provider may be referred to a Memory Clinic if they exhibit early symptoms of ADRD. A Memory Clinic often is staffed by neurologists and other health specialists who specialize in the diagnosis and care of persons with memory disorders such as ADRD. These clinics offer highly specialized diagnostic evaluation and care management that often goes beyond what can be offered in primary care. These specialized clinics are an integral part of the service structure necessary for the well-being of people with ADRD because they assist in the early detection and treatment of Alzheimer's disease, which can greatly improve patient's quality of life and life expectancy. **There are six memory clinics in Iowa, and they are all located in more urban areas such as Des Moines and Cedar Rapids. This number is lower than many peer states. For example, Wisconsin has a large network of 40 memory clinics that provide specialized care (Wisconsin Alzheimer's Institute, N.D.).**

Area Agencies on Aging

Iowa has a network of Area Agencies on Aging that provide case management, care coordination, meal programs, caregiver support, respite services, health and recreation programming, educational events, and a variety of other services to Iowa's aging population and their families. There are six Area Agencies on Aging (AAA) in Iowa that work in coordination with the Iowa Department on Aging (IDOA). Collectively, they serve over 100,000 community members across Iowa every year. While some number of AAA programs address brain health, memory loss and ADRD, **efforts to increase the role of the AAA to expand awareness about ADRD, early diagnosis, and other services available to Alzheimer's patients is essential.**

Expanding awareness about ADRD and early diagnosis and services available to Alzheimer's patients is essential.

Health Insurance Plans

Medicare and supplemental insurance plans allow persons with dementia access to life-saving care that can also address a variety of their needs. As public health professionals recognize, it is important to address social determinants of health in insurance plans because unfavorable determinants can foster poor health outcomes and health inequalities (Braveman and Gottlieb, 2014). Major health systems in Iowa have become more involved with the effort to address social determinants of health. This effort to address social determinants will help people with ADRD as this population is especially vulnerable to social isolation, food insecurity, transportation, difficulties with activities of daily living, financial fraud and navigating increasingly complex institutions. Industry partners and the health plans they administer can help ensure that a patient who lives with ADRD has access to the resources that they need. **Although purchasers are often an invisible participant in service utilization, their cooperation is essential to improving and expanding Alzheimer's care.**

Adult Day Care and Home Care

As a person who lives with ADRD experiences declines in their ability to complete activities of daily living by themselves, many of them need additional help at home. The majority of people in the aging population prefer to live at home as long as possible (Callahan et al. 2017). Home healthcare services and respite services like adult day care facilitate this. Unfortunately, Iowa does not offer an adequate supply of programs and services for home health and respite care. There are 105 Home Health service agencies registered with the Center for Medicare and Medicaid Services. This equates to roughly one home health service per county in Iowa. However, these are concentrated in urban centers and there appears to be a lack of home health services in rural counties. The Alzheimer's disease estimates suggest that there are from 112 to 406 people with ADRD in a smaller county like Crawford that has a 65+ population of 2,900 people. Even at the lowest estimate, one home health agency would struggle to care for 112 people who may need their services. There would need to be multiple home health agencies in Crawford County to care for the high estimate of 406 people. Additionally, these home health service agencies care for a wide variety of individuals with disabilities and other needs, so it is likely that their caseloads are already relatively full with clients who do not have an ADRD diagnosis. There is no comprehensive data available about the training and Alzheimer's disease specific resources these home health service agencies have, and it is highly likely that most agencies have staff training in caring for persons living with ADRD. Due to the challenging nature of working with patients who are in cognitive decline, it is integral that the services these patients seek are specific to the needs they have.

There are similar concerns about the supply of Adult Day Care Centers in Iowa. These organizations are a type of respite care service that allow caregivers of persons living with ADRD to enroll them in an Adult Day Care Center that has activities, assistance with activities of daily living, and meals provided to them. Adult Day Care Centers provide appropriate social interactions for these persons that can increase their quality of life. Additionally, Adult Day Care Centers allow caregivers more flexibility to complete tasks that are otherwise very difficult to accomplish while providing care for a person living with ADRD (Zabalegui et al. 2014). The assessment identified approximately 25 Adult Day Care Centers in Iowa. Similar to home health service agencies, it appears that very few of these centers are located in non-urban areas or have the resources to take care of persons living with ADRD. This was one of the most significant resource gaps we found in our evaluation. These services are especially important because they allow persons living with ADRD and their caregivers the opportunity to live as independently as possible.

Assisted Living Facilities with Memory Care

Many persons with ADRD seek residency in assisted living facilities when they can no longer live independently and do not have sufficient caregiving support at home. The State of Iowa does regulate which assisted living facilities are considered "dementia-specific" facilities, however the term dementia-specific is generally not used in consumer-facing resources about Assisted Living Programs.

Iowa Administrative Code, Chapter 69, Assisted Living Programs defines dementia-specific assisted living programs as a program that:

1. Serves fewer than 55 tenants and has five or more tenants who have dementia between Stages 4 and 7 on the Global Deterioration Scale, or
2. Serves 55 or more tenants and 10 percent or more of the tenants have dementia between Stages 4 and 7 on the Global Deterioration Scale, or
3. Holds itself out as providing specialized care for persons with dementia, such as Alzheimer's disease, in a dedicated setting.

This definition does not include provisions about the types of services available to persons living with dementia at the facility. Furthermore, the code states that assisted living facilities are defined as dementia-specific based on the occupancy of residents with dementia:

> *"69.2(3) Dementia-specific program by definition. If a program meets the definition of a dementia-specific assisted living program during two sequential certification monitorings based on the number of tenants served who have dementia between Stages 4 and 7 on the Global Deterioration Scale, the program shall be deemed a dementia-specific program by definition. If the number of tenants served who have dementia between Stages 4 and 7 on the Global Deterioration Scale goes below that which is required by the definition of dementia-specific program at any time after the program has been deemed dementia-specific by definition and the program is not holding itself out as providing dementia care in a specialized setting, the program will no longer be considered dementia-specific".*

While not problematic, the regulated definition of dementia-specific Assisted Living Programs does not take into account the services that are provided to persons living with dementia. This is in contrast to the unregulated term memory care that is used to market facilities as specialized in the care of persons living with ADRD. This discrepancy can generate confusion for or mislead patients and caregivers who are seeking assisted living facility placement. Iowa's assisted living facilities may or may not offer evidence-based care for persons living with dementia even though they can advertise as offering "memory care." Some facilities offer evidence-based memory care programs and train staff in dementia care, but many do not. The assessment identified 55 Iowa assisted living facilities that offer evidence-based programming to help preserve a resident's memory. **The cost of assisted living facilities is prohibitive for most Iowans. According to the Iowa Department of Human Services, the average monthly cost of Assisted Living in Iowa is $7,250.40 in 2021. This is further complicated by the problem that many insurance plans and Medicare do not cover assisted living facility costs.**

Nursing Facilities with Chronic Confusion and Dementing Illness Units

Nursing facilities offer a more advanced level of care than assisted living facilities as they have in-house clinical nursing staff who can assist with medical needs and events. Many persons with ADRD who need the most advanced level of care live in nursing facilities with Chronic Confusion and Dementing Illness (CCDI) units. CCDI units have a special license classification for nursing facilities that offer dementia specific clinical services in the nursing facility. There are 102 CCDI units in Iowa that have a total of 2,045 beds.

The cost of assisted living facilities is prohibitive for most Iowans. The monthly average is $7,250 in 2021.

Prominent Gaps in the Landscape

Considering the epidemiological estimates of ADRD in Iowa and the programs and services in place, it appears that there are significant gaps between the needs of persons living with ADRD and what is currently available. There currently are anywhere between 20,000 and 70,000 people in Iowa who live with ADRD and this number is expected to steadily increase as the aging population grows larger. We have found that there are 96 neurologists and 33 geriatricians in the state, six memory clinics, 25 Adult Day Care Facilities, 105 general home health service agencies, 55 evidence-based Memory Care Assisted Living programs, and 102 CCDI units in the state. **Ideally, Iowa would have a more robust community-based home service infrastructure to enable persons who live with ADRD to live as independently as possible, for as long as possible, at home. A strong community-based resource network will enhance the well-being and quality of life for these people and their caregivers.**

Our findings suggest that this undersupply of community-based services can be, in part, attributed to a lack of public education about ADRD and a corresponding lack of demand for evidence-based services. Conversely, health care providers are not likely to develop ADRD programs and services without a defined community need or patient demand. It is likely that many Iowans are unaware of the critical role that annual screening, full on assessments may play and they may not be aware of how Home Health Services, Adult Day Care Services, memory clinics, and other community-based support services could help with their preference to stay at home as long as possible.

There are significant gaps between the needs of persons living with ADRD and what is currently available.

CDC Healthy Brain Initiative State Roadmap Goals

Iowa is not the only state to face gaps related to the difference between the ADRD programs and services needed and the services provided. At the national level, the CDC established the *Healthy Brain Initiative* as a means to disseminate evidence-based resources to state and local communities to improve and expands programs and services for persons living with ADRD and their caregivers. *The Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: the 2018-2023 Roadmap* is a comprehensive guidebook published by the CDC to help states address problems related to the lack of awareness and infrastructure for these persons. This Roadmap provides specific interventions and techniques that can be applied directly to state's current operations. In fact, the Roadmap can be immediately embraced by states such as Iowa that do not have a dedicated strategic plan for addressing ADRD. In particular, the CDC roadmap highlights four goals (with objectives) that support the improvement and expansion of evidence-based dementia care.

The four core goals of the Action Agenda are:

1. Educate and Empower
2. Develop Policies and Mobilize Partnerships
3. Assure a Competent Workforce
4. Monitor and Evaluate

The conceptual framework for the State Road Map demonstrates that these four core goals are integral to the broader mission of eliminating health disparities, leveraging resources for sustained impact, and collaborating across multiple sectors. These areas are all informed by applied research and translation of that research into practical public health measures. The visualization of the Roadmap conceptual framework is displayed in **Figure 2**.

The IDPH can adopt the goals and relevant recommendations from the CDC Healthy Brain Initiative State Road Map to address and improve the lives of persons living with ADRD and their caregivers. In fact, Iowa has already made significant progress in the core goal areas of Develop Policies and Mobilize Partnerships, Assure a Competent Workforce, and Monitor and Evaluate. For example, the six Iowa AAAs and the IDOA are highly efficient at developing regulatory policy and mobilizing state partnerships to expand access to existing resources, and have successfully implemented the "No Wrong Door" system as recommended by the *2017 Iowa Access to Dementia Specific Care Final Report*. Iowa has also taken action to assure a competent workforce; the 2015 IDOA Intra-agency Dementia Proficient Workforce Task Force identified how to address workforce training and education concerns related to the care of persons living with ADRD.

Figure 2, CDC Roadmap Conceptual Framework

Iowa has taken action to assure a competent workforce with training and education.

Educate and Empower

The CDC Roadmap goal concerning **Education and Empowerment** is the foundational element of the Roadmap that can facilitate further success as efforts progress toward the other goals. The CDC has identified education and empowerment of the public at large, health care providers and people personally affected by ADRD as an integral goal to improving public health concerns about this issue. **Table 2** displays the seven goals of the Educate and Empower component, enumerated E-1 through E-7.

Table 2, CDE Educate and Empower Goals

E-1	Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis.
E-2	Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the lifespan.
E-3	Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.
E-4	Promote prevention of abuse, neglect, and exploitation of people with dementia.
E-5	Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.
E-6	Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia.
E-7	Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.

The CDC writes that the outcome of the Educate and Empower component is two-fold: to inform the public (including health care providers) and to inform people with ADRD and their caregivers. The general public awareness goals include a basic understanding of what Alzheimer's disease is and how it affects a person's life, the behavioral risk factors that can be reduced through healthy lifestyle, and an awareness of the resources that exist to help people with ADRD live a safer and more fulfilling life even as they experience the disease. An important component of this work is to reduce the stigma associated with ADRD; stigma and fear about Alzheimer's due to a lack of awareness about the disease and available treatment fuel the cyclical lack of resources and support for those with ADRD because people feel uncomfortable discussing dementia and Alzheimer's disease. As the public becomes informed about ADRD, stigma of the disease will be reduced because people will learn that public health measures can support the lives of Alzheimer's patients and reduce their hardships.

One of the primary outcomes associated with educating persons who have ADRD, and their caregivers is supporting efforts that allow people to live at home as long as possible. Arguably, one of the reasons that the public and individuals affected by this disease and disorders do not have many community-based options is that they are not aware those services exist. The Roadmap explains that community-based programs including home health, adult day care and respite care are essential supports that can greatly improve the chances of remaining at home and supporting quality of life. By educating the public that these services exist, consumer demand will be increased.

A primary outcome of education on ADRD is allowing people to live at home as long as possible.

Iowa's Current Actions to Educate and Empower

The State of Iowa has made strides in education and empowerment initiatives related to ADRD that offer a solid foundation to build upon in increasing public awareness of the disease and its management. A review of several recent activities that have worked to promote public awareness of ADRD and identify next steps that the IDPH may take to expand this work follows.

Iowa State Plan on Aging 2017-2021

The Iowa State Plan on Aging 2018-2021 offered three goals to improve the lives of the Aging population.

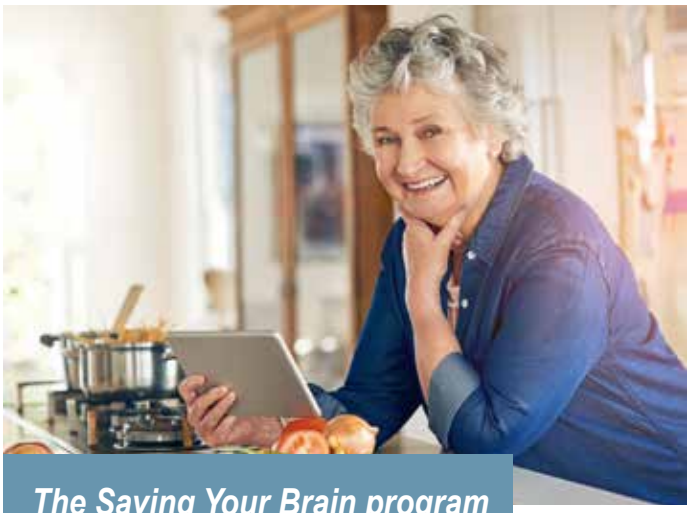
The first goal is to support all older Iowans (not just those who live with ADRD) and their caregivers to make informed decisions and exercise self-determination to sustain their independence, well-being, and health. One component of this goal was to ensure statewide access to resources and options for a variety of services to help people remain as independent as possible. The assessment of home and community-based care in Iowa indicates that industry partners will be essential to expanding this care because the sustained support of providers and purchasers is essential to long-term service provision.

The second goal is "enabling Iowans to stay in their own residence and community of choice through the availability of and access to high-quality home and community services and supports including support for families and caregivers." The report identifies service gaps in home and community-based services and finds that continuous funding for service providers through Medicaid or other payment options is one of the biggest barriers to long-term industry involvement in this goal. This finding comports with our resource survey conclusions.

The third goal of the State Plan on Aging is to protect the rights of aging adults and prevent the abuse or exploitation of older Iowans. The CDC's Road Map Educate and Empower goals align with this vision by improving public knowledge of ADRD and related dementias and reducing the associated stigma.

Saving Your Brain

Broadlawns Medical Center, the YMCA of Greater Des Moines and Telligen launched a public awareness initiative and evidence-based, multi-session program, Saving Your Brain, which educates the public about risk factors for cognitive decline and actions they can take to reduce their risk of dementia. The Saving Your Brain program has multiple points of entry for participants. It offers a personal risk assessment quiz hosted on the IDPH website that asks a comprehensive set of questions about the participant's lifestyle and health behaviors. This evidence-based resource then estimates the participant's risk for developing dementia based on their survey responses and offers a personalized and comprehensive list of recommendations to participants at no charge. The Saving Your Brain program offers a 10-week educational program that was launched in 2021. There were 65 participants in the first session. The second session, scheduled for summer 2021, had already met its enrollment capacity. There are 70 additional people on the waiting list for the fall session. This project is in direct alignment with CDC roadmap education and empowerment goal.



The Saving Your Brain program educates the public about risk factors for cognitive decline and actions they can take to reduce their risk of dementia.

Iowa Area Agencies on Aging: Education

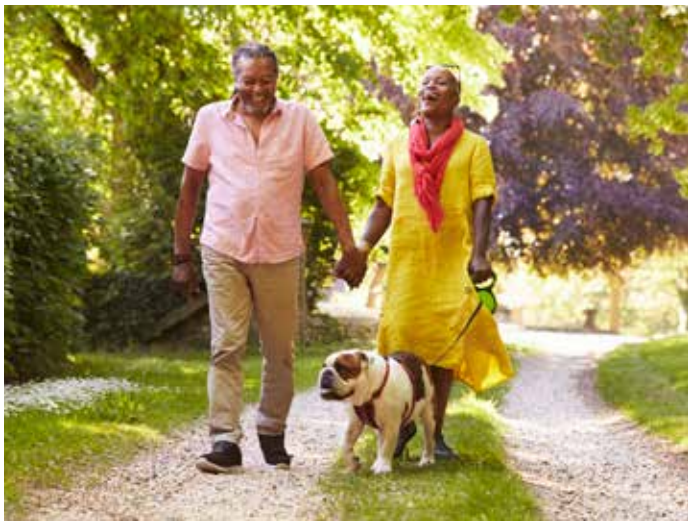
The Iowa Area Agencies on Aging all engage in providing information and education about programs and services pertaining to all older Iowans including those with dementia. While ADRD is not a specific target, a review of each AAAs most recent annual report provides encouraging evidence that the AAAs are each working towards Educate and Empower goals that are aligned with the CDC roadmap recommendations. Many of Iowa's AAAs offer similar services that can address the needs of people with ADRD and their caregivers. For example, Aging Resources of Central Iowa provides adult day care, case management, respite care, and other ADRD-related services to clients. Elderbridge Area Agency on Aging also provides in-home and out-of-home respite care services and case management. Heritage Area Agency on Aging provides options counselling and case management, in addition to an Elder Rights program that can serve those with ADRD. The Northeast Area Agency on Aging provides respite care and caregiver services, in addition to a nutrition assistance program. Milestones Area Agency on Aging provides caregiver assistance, abuse prevention services, and nutrition assistance programs. The Connections Area Agency on Aging also provides nutrition programs, educational outreach, and elder abuse consultations.

Dementia Friends of Iowa

A new program has been established in Iowa through collaboration between Dementia Friendly America, the Gerontology Society of Iowa, and the Aging & Disability Resource Center network. Dementia Friends Iowa is modeled after programs by the Dementia Friendly America Initiative to increase public awareness of dementia and reduce stigma associated with dementia and cognitive decline. This program will offer public education programs and train "Dementia Friends Champions," who are laypeople that become community ambassadors to improve awareness of dementia and increase community acceptance. Dementia Friendly America is associated with the United Kingdom Alzheimer's Society.

Iowa Alzheimer's Association

The Iowa Alzheimer's Association has a long-standing and productive partnership with state public health agencies and industry partners. It hosts a variety of educational events for persons living with ADRD and their caregivers about the disease course, coping with a changing lifestyle, and research-informed intervention techniques for caregivers. The Alzheimer's Association also has national awareness campaigns and publishes a yearly *Facts and Figures* report that is an important source of information about Alzheimer's epidemiology, the economic impact of the disease, and insurance and service access issues, among other topics. The Association also has the *Community Resource Finder* on its website that can help people find educational programs, home health services, community-based services, housing options, and medical services for people who live with ADRD.



There are many services available in Iowa to help with Alzheimer's and Dementia related issues.

Discussion and Conclusion

This report reviews the landscape of Alzheimer's disease and related dementia in Iowa, including disease estimates, program and service supply, the CDC Roadmap goals pertaining to education and empowerment, and Iowa's current activities related to education and empowerment of people who live with ADRD or cognitive decline and their caregivers. The resources provided by the CDC Roadmap offer many strategies and examples for how to improve and expand efforts concerning education and empowerment.

For example, Iowa can look to the work performed in California, where the California State Plan for Alzheimer's Disease 2011-2021 set goals to secure public, private, corporate and philanthropic funding sources to address concerns about ADRD-related public health issues. The State Plan identified education as a crucial element to advancing the care of people with ADRD. Partnerships between state, non-profit, and industry organizations allowed for the development of a broad-based, statewide educational campaigns that involves public awareness campaigns. These campaigns included topics such as stigma reduction, caregiver resources, cultural competence in ADRD care, and other issues that enhance the delivery of care for people with ADRD. The California State Plan on Aging allowed for the creation of several discrete community-based programs offered in libraries and senior centers such as "Healthy Living for Your Brain and Body" and "Warning Signs of Alzheimer's."

In addition, Iowa may look to accomplishments in Wisconsin. The state of Wisconsin has benefited from partnerships between state organizations and academic centers to develop public health infrastructure that is more responsive to the needs of people with ADRD. The Wisconsin Department of Human Services created the Wisconsin Health Brain Initiative and published the Toolkit for Building Dementia-Friendly Communities which outlines a variety of actions taken by state, non-profit, corporate, and academic partnerships to improve the wellbeing of people with ADRD. These projects include a toolkit for business to meet the needs of customers with ADRD, expanding their network of Adult Day Care centers, and comprehensive caregiver resources. The Wisconsin Alzheimer's Institute at the University of Wisconsin works to provide community outreach, disease research, and new initiatives to improve patient care. Coalitions across state sectors in Wisconsin have also developed materials to support education efforts about dementia and supported a public awareness campaign about ADRD, highlighting the services and resources available to support people with dementia and their family caregivers. These campaigns include social media, radio and newsprint.

By offering such great examples being pursued in other states, the CDC Roadmap allows Iowa to take immediate and practical steps to improve the lives of persons who live with ADRD and their caregivers through education and empowerment. The expansion of education and awareness of ADRD will help Iowans realize that with the right care and structural support, all people can live with dignity and wellness at any stage in life.

The CDC Roadmap allows Iowa to take immediate and practical steps to improve the lives of persons living with ADRD and caregivers through education and empowerment.

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