

# 2020

## KANSAS ALZHEIMER'S DISEASE PLAN



# 2020 Kansas Alzheimer's Disease Plan

## Table of Contents

1. Vision Summary
2. Process for Preparing the Kansas Alzheimer's Disease State Plan
  - A. Executive Order
  - B. Members of the Task Force
  - C. Committees
  - D. Survey
3. Face of Dementia in Kansas
  - A. Definition
  - B. Most Dementias
  - C. Diversity
  - D. Diagnosis
  - E. Risk Factors
  - F. Prevalence
  - G. Costs
4. Policies and Recommendations
  - A. Research and Data Collection
  - B. Rural Kansas
  - C. Safety and Legal Issues
  - D. Training and Workforce
  - E. Public Awareness
  - F. Access to Care
  - G. Family Caregiver
  - H. Care For All With Dementia
5. Glossary
6. Appendix

## Vision Summary

As Kansans prepare to address the challenges associated with Alzheimer's and other dementias, we want to assure that all Kansans are aware of and comfortable talking about aging issues and topics inherent to the aging process including Alzheimer's and other dementias; safety, legal and financial issues, preparation for end of life care, the need to create aging and dementia friendly communities, issues specific to rural areas of the state, a dementia-capable workforce, and access to care.

## Process for Preparing the Kansas Alzheimer's Disease State Plan

### Executive Order

On May 2, 2019 Gov. Laura Kelly signed an Executive Order creating the Alzheimer's Disease Task Force. The purpose of the Task Force was to continue the progress of the Alzheimer's Disease Working Group which met in 2018. The Task Force began meeting in August 2019 in Topeka. Members were from across the state, city and rural, and from various backgrounds and connections to the disease. The report is due to Governor Laura Kelly on January 13, 2020. (See appendix for full Executive Order)

### Members of the Task Force

Members of the Task Force represent multiple industries and stakeholder groups including:

- The Alzheimer's Association
- Caregivers
- Nursing Facility
- Assisted Living
- Medical Care Provider
- Disease Researcher
- Person with the disease
- Psychologist in Geriatric Care
- Elder Law Attorney
- Silver Haired Legislature
- Law Enforcement
- Elected official
- Area Agency on Aging

### Committees

The Task Force was made up of eight committees which met throughout the fall: Public Awareness, Access to Care, Family Caregivers, Training and Workforce, Safety and Legal, Research and Data, Dementia Care, and Rural.

### Survey

In the fall of 2019, for a six-week period, the Task Force conducted a survey to obtain public comment and input on the needs of Kansans. It was distributed widely to areas throughout the state and to various types of stakeholders both to family caregivers and professional caregivers. A total of 1066 surveys were completed during that time. The survey included multiple choice questions as well as open-ended questions so respondents could share their own recommendations. For a full survey report refer to the Appendix E.

# Face of Dementia in Kansas

## Definition

Alzheimer's disease is a degenerative brain disease and the most common form of dementia. Dementia is not a specific disease. It's an overall term that describes a group of symptoms. Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain. Alzheimer's is the most common type of dementia, but there are many kinds.

## Most Common Dementias



*For a complete list of the most common types of dementia, please refer to Appendix B.*

## Diversity

Kansas' population is growing increasingly more diverse. The State of Kansas should encourage partnerships with multicultural coalitions, and other groups that represent underserved populations including rural communities, racial and ethnic minorities, veterans, members of the LGBT community, individuals with younger-onset Alzheimer's disease, individuals with intellectual and developmental disabilities, and individuals with traumatic brain injuries. These partnerships should be built in order to develop and expand dementia-supportive services to diverse individuals and families across the continuum of care (including, but not limited to, adult day care centers, physicians, home-based providers, assisted living communities, skilled nursing facilities, and specialized dementia care entities). It is imperative that the state provide access to diagnosis and quality health care for all individuals affected by Alzheimer's and other dementias.

# Diagnosis

There is no single diagnostic test that can determine if a person has Alzheimer’s disease. Physicians (often with the help of specialists such as neurologists, neuropsychologists, geriatricians and geriatric psychiatrists) use a variety of approaches and tools to help make a diagnosis. Although physicians can almost always determine if a person has dementia, it may be difficult to identify the exact cause.

On average, people with Alzheimer’s disease live for eight to ten years after their symptoms begin. However, life expectancy does vary considerably depending on how old the person is along with other factors.

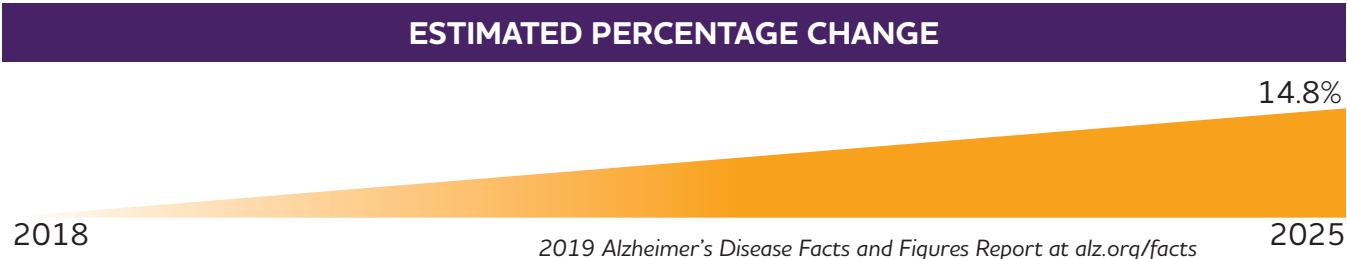
# Risk Factors

Experts agree that in the vast majority of cases, Alzheimer’s, like other common chronic conditions, probably develops as a result of complex interactions among multiple factors, including age, family history, genetics, environment, lifestyle and coexisting medical conditions. Although some risk factors — such as age or genetics — cannot be changed, other risk factors — such as high blood pressure, diet and exercise — usually can be improved to help reduce risk. Research in these areas may lead to new ways to reduce the risk of developing Alzheimer’s and other dementias.

# Prevalence

In Kansas, 54,000 people age 65 years and older are living with the disease. It is estimated that the number will increase to 62,000 by year 2025 which is a 14.8 percent increase. Alzheimer’s is the sixth leading cause of death in all Kansans. It is estimated that there are 5.8 million Americans living with Alzheimer’s. There are also approximately 151,000 caregivers and family members in Kansas who provide care and support for someone with the disease. With this expected increase in the prevalence of this disease, availability, and accessibility of services for individuals and families impacted are critical factors in dementia services.


NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER’S BY AGE				
YEAR	65-74	75-84	85+	TOTAL
2019	7,400	22,000	24,000	54,000
2020	9,000	27,000	26,000	62,000



## Costs


Treating persons with the disease is very expensive. Currently, Alzheimer's disease is the most expensive disease in America, costing more than cancer and heart disease. The financial costs of Alzheimer's for families and the government are enormous. The direct costs to American society of caring for those with Alzheimer's and other dementias will total an estimated \$290 billion. In 2019, Kansas spent \$441 million Medicaid dollars on individuals with this disease. These costs are expected to increase 21.7 percent by 2025.

Given the cost of Alzheimer's, it is easy to see how the financial burden of providing care can wipe out a person's savings. The burden is even heavier for those 7.3 percent of Kansans (over 211,000) 65 years of age or older who are living in poverty. The 29 percent of older adults living alone with Alzheimer's disease, without family members to assist in their care, are at particularly high risk of problems in both obtaining quality care and paying for it. Individuals who are diagnosed with Alzheimer's disease before they reach retirement age are also likely to face financial hardship due to loss of employment and inadequate insurance. Alzheimer's disease exacts a substantial burden not only on those affected but on their families, friends and communities as well. An estimated 151,000 Kansans provide unpaid care valued at nearly \$2,173,000,000 for people with Alzheimer's disease.



Cost of Care

Genworth



Kansas - State

Monthly Cost

2019

Home Health Care

Homemaker Services

\$4,004

Homemaker Health Aide

\$4,195

Based on annual rate divided by 12 months (assumes 44 hours per week).

Adult Day Health Care

Adult Day Health Care

\$1,733

Based on annual rate divided by 12 months.

Assisted Living Facility

Private, One Bedroom

\$4,473

As reported, monthly rate, private, one bedroom.

Nursing Home Care

Semi-Private Room

\$5,627

Private Room

\$6,175

Based on annual rate divided by 12 months.

<https://www.genworth.com/aging-and-you/finances/cost-of-care.htm>

## **Policies and Recommendations**

### **Research and Data Collection**

#### **Improving Research and Data Collection in Kansas**

Research that discovers a way to delay the debilitating symptoms of Alzheimer's by just five years could cut prevalence rates in half. Research is also the only means by which we will be able to cure and ultimately prevent this tragic disease. Research efforts in Kansas have accelerated in recent years, advancing our understanding of Alzheimer's disease, testing new prevention and therapeutic strategies and developing new models of care. These efforts have set the stage for Kansas to become a national leader in fighting Alzheimer's disease. Action is still needed in the promotion of research and data collection in our state. Identifying new and effective treatments, cures, prevention strategies, and collecting data for Alzheimer's and other dementias are critical in addressing this public health crisis.

Kansas research entities have been at the forefront of Alzheimer's research, especially in the areas of causes of Alzheimer's disease, models of care, treatment and prevention. Alzheimer's disease research in the United States is funded primarily by the National Institute on Aging (NIA) of the National Institutes of Health (NIH). In 1984, the NIA established five Alzheimer's disease Centers (ADCs) across the country to advance clinical care. Kansas is one of only 21 states to have a nationally designated Alzheimer's Disease Research Center. Since receiving this designation in 2011, the University of Kansas Alzheimer's Disease Center (KU ADC) has made strides in preparing the state for the rising prevalence of Alzheimer's disease. Researchers, clinicians, and educators at other state universities and hospitals, including Kansas State, Emporia State, Wichita State, Ascension Via Christi Research and KU Wichita, among others, are also making an impact.

Scientists in Kansas are hard at work to determine better ways to diagnose the disease and develop cures. The KU ADC is at the forefront of clinical trials, developing novel drugs and partnering with others to test a variety of approaches to stop, slow, or prevent the disease. As one of 35 national sites to participate in the U.S. Department of Health & Human Services, National Institute on Aging's, Alzheimer's Clinical Trial Consortium, the KU ADC brings the most innovating and cutting-edge trial opportunities to Kansas.

Ascension Via Christi Research (AVCR) has conducted clinical trials in Alzheimer's disease for the past 27 years. AVCR has participated in approximately 20 multicenter and investigator-initiated research studies testing various investigational medications to treat and prevent Alzheimer's disease, including the currently FDA approved medications and Aducanumab, which will be taken to the FDA for possible approval in 2020, the first new medication to possibly be FDA approved in 19 years. ACVR is also working with the Alzheimer's Association to develop a partnership between research, primary care and mental health focused on caring for the caregivers. Those caring for family members with

Alzheimer's disease have their mental and physical health negatively affected by the stress. This will focus on quantifying data on caregiver stress and making appropriate referrals to primary care and mental health professionals.

Kansas scientists also have unique drug development efforts and have helped usher in an entirely new field of prevention science. In addition, researchers across the state are investigating how to best care for the increasing number of individuals with Alzheimer's disease.

New models of care are required to stem the rising tide of Alzheimer's and better deliver today's treatments and tomorrow's cure. A public health crisis of this magnitude requires a unified community approach that aligns all the key stakeholders, with primary care physicians at the forefront. Kansas researchers are beginning to test new models of care that increase the reach of the highest quality caregivers, reduce costs and lower the health burden on patients and families. More experts dedicated to fighting this disease are needed to transform our efforts to fight Alzheimer's disease now and in the coming years. There is a critical shortage of physicians, nurse practitioners, and social workers. State universities in Kansas have developed training programs to successfully launch young physicians, scientists, and health care workers into the fight. Kansas needs a robust education and training effort to continue to develop the next generation of scientists, clinicians, and other frontline health care workers fighting the disease.

## Recommendations

### 1. Public Awareness

Increase awareness of Alzheimer's research and clinical trials by promoting on state websites (e.g. Kansas Department of Health and Environment (KDHE), Kansas Department for Aging and Disability Services (KDADS), etc.). Ensure that the websites include links to Alzheimer's Association Trial Match, Ascension Via Christi Research, University of Kansas Alzheimer's Disease Research Center, National Institute of Health, and other research centers/programs.

### 2. Statewide Data Reporting System

Implement a statewide data reporting system to improve data collection on the prevalence of Alzheimer's and other dementias in Kansas. Data should be collected from Behavioral Risk Factor Surveillance System (BRFSS), minimum data set (MDS) cognitive impairment data in nursing homes, hospital admissions, mortality, Adult Protective Service calls and cases, death certificate data, and Medicare cognitive assessment data.

### 3. Expand Access

Explore approaches that would enable the expansion of clinical trials to satellite facilities, including training of personnel, telemedicine, and remote video conferencing approaches.

### 4. Funding

Encourage individuals to support funding for dementia research through local research institutions, the Alzheimer's Association, and state universities.

## Rural Kansas

According to the U.S. Census, the total population in Kansas is around 2.9 million; approximately 30 percent of the citizens reside in the urban areas of Wichita, Overland Park, Kansas City, and Topeka. The other 70% of citizens reside in rural communities and may face significant barriers to effective medical care.

Rural communities provide the essentials of life: a place to live, connections with neighbors and friends nearby, local shops, places for social gatherings, areas to work or volunteer, amenities like parks, libraries, places of worship, clinics and a variety of other features.

These communities play a critical role in supporting persons with Alzheimer's and their family caregivers, by providing assistance and surrounding the person with their support. Because of the disease, persons with Alzheimer's need the familiarity of the same physical location and familiar landmarks, people and places. In addition, the caregivers are more likely to reach out for support from trusted friends and neighbors if they live in a community where they feel connected.

There is growing evidence that effective management of chronic disease, including Alzheimer's, requires a commitment to a team approach for care of the patient. Assembling a team while living in rural Kansas proves very difficult. Services for dementia patients to include medical, financial, and legal are sometimes 75 or 80 miles away. Because of that, transportation is a priority. Public transportation to neighboring towns is often available, but unlikely to any urban areas. There are some volunteer driver services, but the demand often exceeds the supply of services available.

Many local programs are funded through public dollars; and are targeted at persons who are low-income and in need of long-term care. The exception to this is the program funded under the federal Older Americans Act that are available to all persons over 60 at all income levels, but targeted to those who are low-income (but not eligible for Medicaid), frail, minority, and isolated.

There are usually three method of payments — Kansas families able to self-pay for services, those who are exhausting their assets, and then those that have already exhausted all assets and are eligible for Medicaid.

There are unique challenges facing rural Kansans, which may include the following:

- Reduced workforce of caretakers due to loss of younger Kansans locating to a more urban area. This population attrition may be contributing factors to the closure of nursing homes and hospitals.
- There are a limited number of assisted living facilities, and an even more limited number equipped to handle a Kansan with Alzheimer's.
- Limited assisted living facilities willing to accept Medicaid.

- Fewer nursing homes with dementia care availability.
- Lack of training of nursing home/assisted living staff in dementia care.
- Lack of respite or day care services.
- Home and Community Based Services (HCBS) in rural Kansas are very restricted and present with unique issues such as a long waiting period for application approval, an overall difficult time navigating the system and limited availability of services.
- Because services are often located in urban areas, transportation becomes a huge issue for rural Kansans. The services would include neurologists, non-profit legal and financial services.
- Treatment of dementia patient in emergency room, as a psychiatric diagnosis.
- Few Alzheimer's and other dementias support groups.

### **Needs applicable to rural Kansas**

- More available caregivers.
- More dementia trained facilities, including nursing/skilled care facilities, assisted living and Home Plus.
- Stabilize rural hospitals.
- Rural transportation services for medical purposes.
- Consumer friendly Medicaid/HCBS with improved response time.
- Alzheimer/dementia support groups.
- Easier access to local neurological services.
- Medicare covered screening for dementia.
- Geriatricians.
- Local respite/day care services.

## **Solutions for rural Kansas**

- Increase funding and support for health services in Kansas.
- An effort must be made to help keep those with Alzheimer's in their home setting until facility care is more beneficial. This can be accomplished by providing caregivers with needed resources.
- Support the establishment of the State Advisory Council and establish focus groups of caregivers in rural areas of Kansas to feed local information to the Advisory Council.
- A concentrated effort to improve dementia care and services, access to community-based care; abundant quality care in residential settings; and expanded funding for research and public programs serving people with dementia.

## **Recommendations**

1. If Medicaid were expanded, it would provide reimbursement to rural hospitals for uninsured and maintain crucial access points.
2. Require dementia training for nursing/skilled care facilities, assisted living, Home Plus, and hospital emergency room.
3. Increase public awareness of rural transportation options – <https://ksrides.org>.
4. Make telemedicine easier to access. Currently it must occur in the health care provider's office and the Medicaid reimbursement for use of that room is \$20. Allow the telemedicine to occur without requiring it be in a health care provider's office; increase the Medicaid reimbursement rate.
5. Increase financial incentives of assisted living and home plus facilities to accept HCBS which would encourage more development of those facilities in rural areas.
6. Expand permission of the use for family caregivers, for HCBS purposes.
7. Provide funding to local hospitals for respite or day care, in under-served areas.
8. Increase Medicaid reimbursement rate to agencies providing HCBS services which would allow those agencies to maintain staff for non-Medicaid cases.
9. Better clearinghouse of information/hotline managed by State of Kansas to allow those in rural communities to access support and care options.
10. Increase funding of Area Agencies on Aging so as to assist in caregiver services.

## Safety and Legal Issues

The diagnosis of Alzheimer's and other dementias will inevitably raise significant legal, safety, and financial issues for the individual and their family. These issues often involve an understanding of complex issues and necessitate professional understanding and guidance. Kansas provides a number of safety and legal services for people with dementia but many of these services are limited, slow to develop, underfunded, or even unknown by the very people who need them. This can lead to easily avoidable crises which cost individuals and the state important resources and time.

Individuals with Alzheimer's and other dementias are a growing population who, as the disease progresses, may become strongly dependent on others and less autonomous in making their own choices. Without proper protections, this results in vulnerability and increased risk for abuse and exploitation. Ensuring the safety, rights and dignity of persons with dementia must involve public laws and regulations that span the policy spectrum and include health and social care, safety systems, financial protection, and preventative legal measures. Furthermore, making information readily available, affordable, understandable, and easily implemented allows for individuals and their families to be proactive and thorough in their planning. This allows the person with Alzheimer's and other dementias to express their individual wishes and to choose who will advocate for their care as the disease progresses. This will save valuable personal and state resources while also giving individuals and families peace of mind.

Kansans in need of legal services may contact Kansas Legal Services (KLS) for assistance. They have 11 locations statewide and serve 102 Kansas counties. There are income guidelines for eligibility for services but anyone living primarily on their Social Security is automatically eligible.

### Recommendations

1. Establish the Alzheimer's Disease Advisory Council and promote efforts to prevent, detect, and address abuse, neglect, mistreatment, and exploitation of persons with Alzheimer's disease by coordinating with the Kansas Attorney General's Elder and Dependent Adult Abuse Prevention Council and other appropriate state agencies.
2. Encourage, promote, and support the use of multi-disciplinary teams (e.g. FAST - Financial Abuse Specialist Team) across the state for complex financial abuse cases.
3. Ensure that important legal forms such as durable power of attorney (healthcare and finances example: [www.ksbar.org/pages/durablepowerofattorney](http://www.ksbar.org/pages/durablepowerofattorney)), living will, transportable physician order for patient preferences (TPOPP), and other essential documents are available and provided free of charge to consumers at public libraries, resource centers, senior centers, Area Agencies on Aging, public health departments, and online via the Kansas Attorney General and KDADS.

4. Engage in a public awareness campaign to make people aware of the availability of important legal forms.
5. Create a comprehensive care planning checklist for people living with Alzheimer's and other dementias and their caregivers with regard to care wishes, living arrangements, treatment options, driving decisions, advance directives, and end-of-life care.
6. Kansas needs to work with the Area Agencies on Aging to increase specific legal service funding and the utilization of Kansas Legal Services for persons with Alzheimer's and other dementias.
7. Mandate that the State of Kansas make a determination of eligibility within thirty days of eligibility, and that failing to do so, make eligibility automatic on the 30th day.
8. Create a navigator position to assist applicants for PACE/HCBS/Medicaid, who are unrepresented/unable to afford legal counsel.
9. Create and make the public aware of the Alzheimer's hotline, for legal, health, and services availability in the caller's region.
10. Consider re-establishing local Medicaid/DCF offices.
11. Establish ongoing and best-practice dementia training for law enforcement and emergency personnel, including hospitals and their emergency rooms.
12. Establish an appeal right through the Office of Administrative Hearings for discharge/transfer appeals from assisted living, Home Plus, and residential board and care homes.
13. Access to free or affordable legal services and financial planning resources.

## **Training and Workforce**

Workforce and training needs span the spectrum from family caregivers who need employer support to professionals in a care setting such as long-term care, post-acute or a hospital. The needs are evident, specifically in the arena of education and communication to better equip those who are in the position to provide care to someone living with dementia.

In 2019, the Kansas Department of Labor lists the 20 most difficult positions to fill in Kansas: #2 is Nursing Assistants, #10 is Registered Nurses and #12 is Licensed Practical and Licensed Vocational Nurses. In addition, there are critical shortages and, therefore, critical challenges to families in finding outside health care supports to assist a person with Alzheimer's and other dementias in a home and/or community supported environment.

There are many Kansans in the challenging position of maintaining a career and raising a family while simultaneously caring for their aging parents. This group of people are often referred to as the Sandwich Generation. They are “sandwiched” between being parents of their own children and being caregivers to their parents. With the onset of Alzheimer’s and other dementias, taking on a larger role in their parents’ lives becomes vital. These individuals must become an advocate for the care of their parents and because of their enhanced role, they can experience increased stress and fatigue physically, financially, socially, mentally, and emotionally.

Cost of care continues to rise due to increased regulatory pressures, facility expenses, and professional caregiver wages. This coupled with the ever increasing life expectancy rates creates a wide span of time that a person with dementia will require care. Between family and professional caregivers, specialized training must be available to provide the best possible care.

The need for education does not stop with care facilities and loved ones. Hospitals in Kansas admit patients with dementia daily. At this time there is no program or training implemented in the State of Kansas to accommodate people with dementia and hospital related visits.

## **Current Offerings & Services**

### **Employee Benefits**

Some employers are starting to offer caregiver leave benefits. Starbucks is offering personal time to accrue based on hours worked so that even part-time employees would accrue caregiver leave. In 2020, Johnson County Kansas Government will be offering 80 hours of caregiver leave benefits per year, separate from vacation and sick leave.

### **Professional Caregiver Training**

Professional caregivers are in high demand across the country and the need for quality trained individuals is not going away. Dementia training is required for long-term care employees; however, this is not clearly defined by the regulations as to what the design or duration of the training is ideal. This requirement only affects those professionals in a long-term care setting. This leaves a gap that needs to be addressed for caregivers who work at hospitals, urgent care facilities, and primary-care offices.

## **Recommendations**

### **1. Employee Benefits**

Employers to provide access to leave time specifically for caregiving of dementia family members. This will protect their personal leave time for illness or vacation to take a much-needed break that can enjoy, instead of using leave time to care for a family member with dementia. Doctor’s appointments, errands, cleaning their loved one’s home, and meeting needs such as laundry or personal hygiene can be difficult

to manage if there is not time allotted to be off work for such tasks. Also, by providing leave such as this, it will help relieve caregiver fatigue and worry of protecting one's employment going through experiences coping with a loved ones' dementia.

## 2. Professional Caregiver Training

Develop a required segment of professional caregiver training (Certified Nursing Assistants and Nursing) that addresses the uniqueness of caring for someone with memory-support needs. The promoted curriculum would include content to provide an effective and supportive approach to caring for individuals with dementia. This training should instill skills that allow the caregivers to enter the healthcare workforce with a solid foundation for providing care to people living with dementia.

Assist hospitals, first responders, clergy, social workers, and medical staff with education for their workforce regarding the dementia disease process, how to interact with someone who has memory-support needs, and training on early on-set dementia.

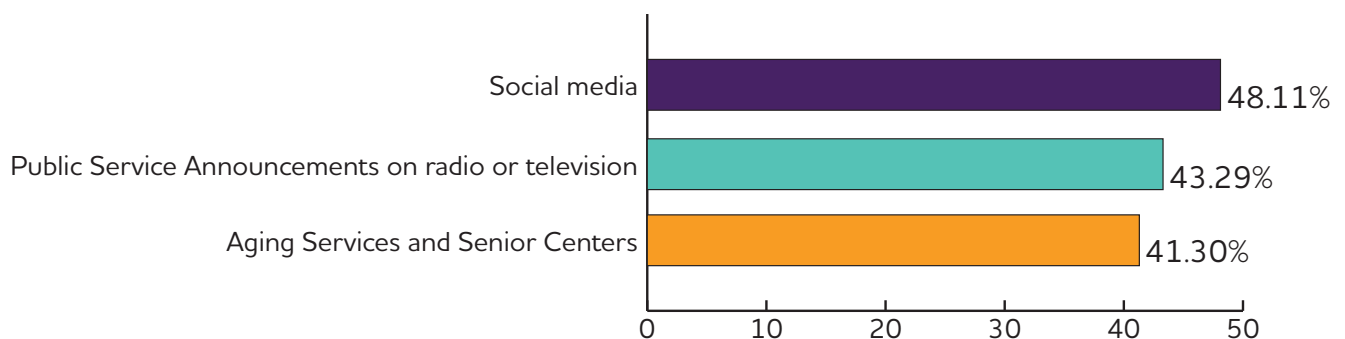
## 3. Professional Caregiver Communication within Medical Facilities

Implement a communication program to support people with dementia care needs through the use of wristbands and medical practices to accommodate these unique circumstances. This would be similar to what is currently done for people at risk of falling.

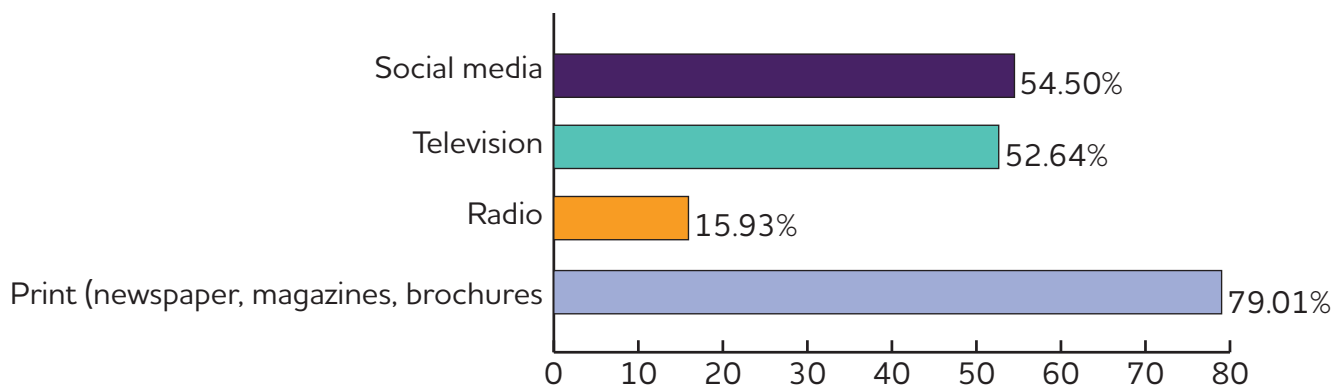
## Public Awareness

To make informed choices, individuals and families impacted by Alzheimer's and other dementias need educational tools to identify the disease, access resources, manage their care, and plan for their futures. Currently, there is no centralized resource within the state of Kansas where families impacted by Alzheimer's and other dementias can turn for this information. State agencies, nonprofits, and healthcare providers offer a variety of educational tools and resources, but the resources often remain "siloe" in these institutions.

***The Alzheimer's Disease Task Force wants to increase general awareness and understanding of Alzheimer's disease across Kansas. In your opinion, which three of the following would be the best ways to raise public awareness?***



### ***Have you ever seen any dementia related material in the following forms in Kansas?***



### ***If an immediate family member was diagnosed with Alzheimer's and other dementias, what outside source would you first contact for help?***

**alzheimer's association™** 56.43%

*2019 Alzheimer's Disease Task Force Survey*

## **Essential Needs**

The State of Kansas needs to coordinate public and private resources to provide state-of-the-art information to Kansans about Alzheimer's prevalence, early identification and the various treatment options for addressing Alzheimer's. By widely educating and informing Kansas communities, the stigma related to Alzheimer's and other dementias will be reduced and the likelihood of early diagnosis will increase. The state needs to develop a coordinated media campaign to reduce stigma, and to increase knowledge of resources available for people with Alzheimer's disease.

## **Recommendations**

### **1. Promote the State Plan**

- Kansas should establish an ongoing Kansas Advisory Council on Alzheimer's and other dementias. Members of the Advisory Council should represent the wide variety of stakeholders impacted by Alzheimer's and other dementias.
- The Public Awareness working group recommends the Kansas Advisory Council on Alzheimer's, as part of its ongoing duties, promote the Kansas State Plan on Alzheimer's disease to stakeholders including Area Agencies on Aging, KU Alzheimer's Research and Disease Center, hospitals, medical professionals, advocacy organizations, municipalities, civic and religious groups.

- Develop links to the State Plan on state-supported websites and social media, and encourage stakeholders to link on their websites and social media.

## 2. Educating about Alzheimer's and other dementias

- The state should create a website that provides a central entry point to link to existing information and resources on Alzheimer's and other dementias.
- Ensure that all state-supported websites have links to this central portal and other reliable information.
- Seek public, private, corporate and philanthropic funding for a statewide education campaign.
- Develop content for a statewide education campaign to address a wide range of issues and audiences.
- Ensure that the public awareness campaign addresses the diverse ethnic, cultural, linguistic, and literacy differences of Kansans.
- Develop specific campaigns for vulnerable and high-risk populations.
- Identify and engage non-traditional partners who are trusted messengers in Kansas communities, including Kansas State University Research and Extension, banks, schools, faith communities, to help connect Kansans to information.
- Promote realistic and positive images of Alzheimer's patients and their caregivers to overcome existing public stigma.

## Access to Care

### Improving access to dementia care and supportive services

Access to services varies depending on public and provider awareness. There is much confusion about the prognosis of Alzheimer's disease, and what services may be available to help caregivers and families of those with Alzheimer's and other dementias. Understanding what services are needed at what stage of the disease can add to the confusion in understanding what services are appropriate and available to help caregivers and families along a continuum at the point that services are being sought. It is essential that education about the disease, detection, diagnosis and treatment are available in tandem with the resources to match the needs. Whether in a metropolitan area, such as Kansas City, or in a rural community, such as Hays, Kansans require access to up-to-date information on detection, diagnosis, treatment, and a variety of health services. Many

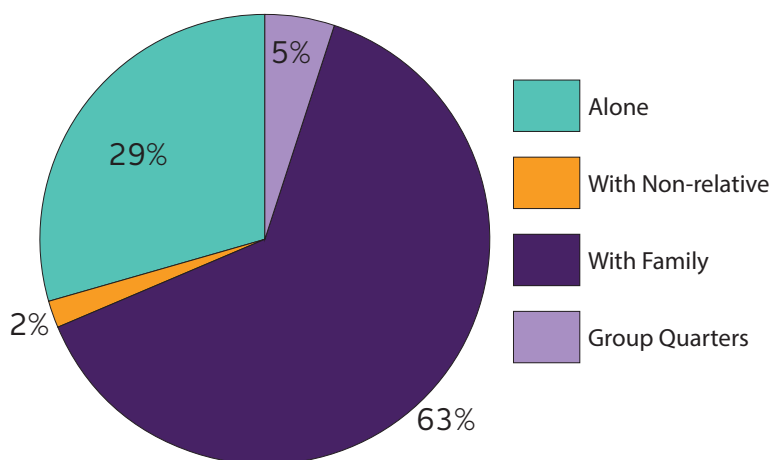
persons with Alzheimer's disease and their families are not aware of specialized diagnosis of the disease through neurological examination and the availability of care and treatment options. This problem is compounded because of the distance to services or a lack of awareness of specialists to consult. Kansans deserve quality diagnosis and treatment informed by the most current science regardless of where they reside in the state.

As the number of individuals living with Alzheimer's and other dementias grows, the more difficult accessing care and services can become. Over the past decades, the racial and ethnic composition of the population in Kansas has changed. There has been an increase in the number of minorities and a decrease in the number of white, non-Hispanic Kansans, as well as a population shift from rural areas into urban and semi-urban communities. Changes in the composition of the population could affect health care needs and require the health care system to evolve in order to address social determinants of health that are often distributed differently across population groups. (<https://www.khi.org/policy/article/17-39>)

It is important to note that only about 5% of older Kansans (65 and older) live in group quarters, this includes independent living communities, assisted living (including Home Plus and Residential Health Care Facility), and nursing facilities. That leaves 63% living with family, 2% with a non-relative, and as stated 29% living alone.

<https://www.seniorcare.com/directory/ks/#key-senior-statistics>

### Who do Seniors live with?



Source: Census.gov

Caring for a person with Alzheimer's disease at home poses significant challenges for caregivers and family members. As the disease progresses the need for support and services both for the person with disease and their caregiver increases. The availability and scope of support varies widely throughout Kansas, with many rural and frontier Kansas communities having limited access to hospitals, and in home service options.

In home care can include a variety of medical and non-medical services. Medical services include care ordered by a physician and provided by licensed professionals including nurses, occupational/speech/physical therapists, social workers and certified nurse aides. This type of care is usually paid by Medicare, Medicaid or private insurance.

### Non-medical services may include:

- Companion services; socializing, supervision, recreational activities and appointments.
- Attendant care; bathing, dressing, toileting, nutrition, exercising and personal care.
- Homemaker services; housekeeping, shopping or meal preparation.
- Case management or coordination of services.
- Home delivered or congregate meal.
- Legal services provided free or reduced cost for persons age 55 years or older by Kansas Legal Services.
- Access to adult day programs.
- Night support for the person with disease so the caregiver can sleep.

\*Non-medical care is usually paid privately, by long-term care insurance policies or through federal and state funded programs.

KDADS' Commission on Aging administers federal and state grant funding to help older adults remain in their homes to prevent or prolong the need for institutional care. Federal funding for the Older Americans Act (OAA) is allocated to each state from the U.S. Department of Health and Human Services Administration for Community Living, Administration on Aging. The funds are distributed to the eleven Kansas Area Agencies on Aging (AAA) who contract with public or private groups to provide services. Services include information and referral, nutrition program, disease prevention and health promotion, in home and community services and caregiver support. In Federal Fiscal Year (FFY) 2017 there were 34,311 unduplicated clients served through the entire OAA program in Kansas. The Senior Care Act (SCA) is funded by State General Funds and by a portion of the Social Services Block Grant. Available funds are allocated to each Area Agency on Aging (AAA) for distribution. The Senior Care Act program provides services in the home to those 60 years of age and older. These services include homemaker, chore, attendant care and case management. Participant's contributions are determined by self-reported income and liquid assets.

Because of the large number of older adults with a dementia living in the home in Kansas, Home and Community Based Services (HCBS) are vital. Low-income persons with Alzheimer's and other dementias who meet the criteria for nursing home care may be eligible for services provided through the Kansas Medicaid program, KanCare. Home and Community Based Services (HCBS) waivers are Kansas Medicaid programs which provide services to an individual in their community instead of a facility. KDADS oversees HCBS waiver programs. These programs require individuals meet both functional and financial eligibility (Medicaid) standards. Data from KDADS shows more than 24,000 people are eligible to receive HCBS.

HCBS services in Kansas that may provide services to individuals with Alzheimer's disease include:

1. Frail Elderly

Services include adult day care, assistive technology, personal care services, comprehensive support, financial management, home telehealth, medication reminder, nursing evaluation visit, oral health services, personal emergency response, enhanced care services and wellness monitoring.

2. Intellectual and Developmental Disabilities (IDD)

Individuals with intellectual disabilities may be eligible if they have impaired function in at least two adaptive skills areas. Services include assistive devices, adult day supports, financial management services, medical alert rental, overnight respite, personal care services, residential supports, specialized medical care, supported employment, supportive home care and wellness monitoring.

3. Institutional Transitions

An Institutional Transition is the process for moving residents of qualified institutional settings into the community. This process identifies individuals who have expressed their desire to return to the community and provides them with supports to aid them in maintaining residence in the least restrictive setting of their choice.

4. Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IID); specific guidelines must be met for the person to be eligible for Medicaid-funded ICF-IID:

- Have active treatment needs as defined by 42 CFR §483.440.
- Be determined program eligible by your local Community Developmental Disability Organization (CDDO).
- Meet the level of care eligibility score.
- Be financially eligible for Medicaid.

5. Brain Injury (BI)

The BI program is for individual's age 0-65 years who have a brain injury that has caused temporary or permanent impairment to their behavioral, cognitive or physical functions who would otherwise require institutionalization in a BI rehabilitation facility. Services include assistive devices, financial management, home delivered meals, medication reminder, personal care services, rehabilitation services, transitional living skills and enhanced care services.

6. Program of All-Inclusive Care for the Elderly (PACE)

The PACE program is designed to promote quality and comprehensive health services for older adults. The primary care physicians and interdisciplinary team of

professionals provide and coordinate all services. Most services are provided in the home and at the PACE Center. The person must be age 55 years or older, certified by the state as meeting the need for a nursing home level of care and must be able to live safely in the community. PACE uses Medicare and Medicaid funds to cover all medically necessary care and services. KDADs is in the process of overseeing the expansion of the PACE program in Kansas from 8 to 59 counties and more than 700 individuals.

With many Kansas communities lacking access to specialists in neurology and neuropsychology, and multiple hospital closures occurring in Kansas, the use of telehealth may become key in assisting individuals and families through the challenges of Alzheimer's and other dementias. In 2018, the Kansas Telemedicine Act was signed into law. This added Kansas to the list of more than 30 states with laws that effectively mandate coverage of telehealth by private payers. (<https://heartlandtrc.org/kansas-telemedicine-act-signed-into-law/>)

Alzheimer's and other dementias is exacerbated by multiple factors: An aging and increasingly diverse population, including growing numbers of persons at elevated risk for Alzheimer's and other dementias; a large proportion of the population living in rural areas where there are fewer health care providers and other resources for persons with Alzheimer's and other dementias and caregivers; the scarcity of clinicians trained in geriatrics and Alzheimer's; and the high cost of care borne by individuals and their families. These challenges require a comprehensive response that mobilizes the residents and health care community of Kansas.

## Recommendations

### 1. Alzheimer's Disease Advisory Council

Create/establish a Kansas Alzheimer's Disease Advisory Council. The Purpose of the council would be to monitor and report progress and to describe barriers to implementation of the state plan. The Advisory Council would be charged with defining the key players to address plan strategies. Reports would be provided to the Governor and Legislature on the continuum of services available, data, trends, and policy recommendations. Individuals appointed may serve renewable two-year periods.

### 2. Affordability/Coverage of Programs and Services

- Address the affordability of services for individuals with Alzheimer's and other dementias by using national data on Medicare and Medicaid spending on dementia, state data on average cost of nursing facilities, assisted living facilities, and in home care services, and using self-reported data on average annual spending on dementia care by individuals with disease and their families.
- The State of Kansas should explore cost-sharing mechanisms and different approaches to finance Home and Community Based Services. These services may include adult day services, meals on wheels, respite care, occupational

therapy, speech therapy, case management services, dieticians, and affordable transportation. Medicaid waivers are a significant factor in helping address the many needs of Kansans dealing with problems associated with Alzheimer's and other dementias.

- It is recommended that Kansas expand the availability of affordable Home and Community Based Services for individuals living with Alzheimer's and other dementias.
- The Task Force recommends the State of Kansas assess the current and future capacity of the Program of All-Inclusive Care for the Elderly (PACE). This is needed in order to determine how this program can be leveraged to address the gaps in services.

### 3. State wide information and referral system

Establish a statewide information and referral system through KDADS, for those with Alzheimer's and other dementias, their caregivers, and their families to enable them to connect with local support services. It is the expectation that the approaches, content, and messaging within these resources help promote well-being and preserve dignity. This should be done in collaboration with existing resource centers including but not limited to: The Alzheimer's Association (Heart of America and Central and Western Kansas Chapters), University of Kansas Alzheimer's Disease Center's Statewide Call Center, Area Agencies on Aging, and county health departments. Promotion should be done by utilizing public service announcements, existing newsletters, and other resources to spotlight where and how to access assistance.

### 4. Telehealth

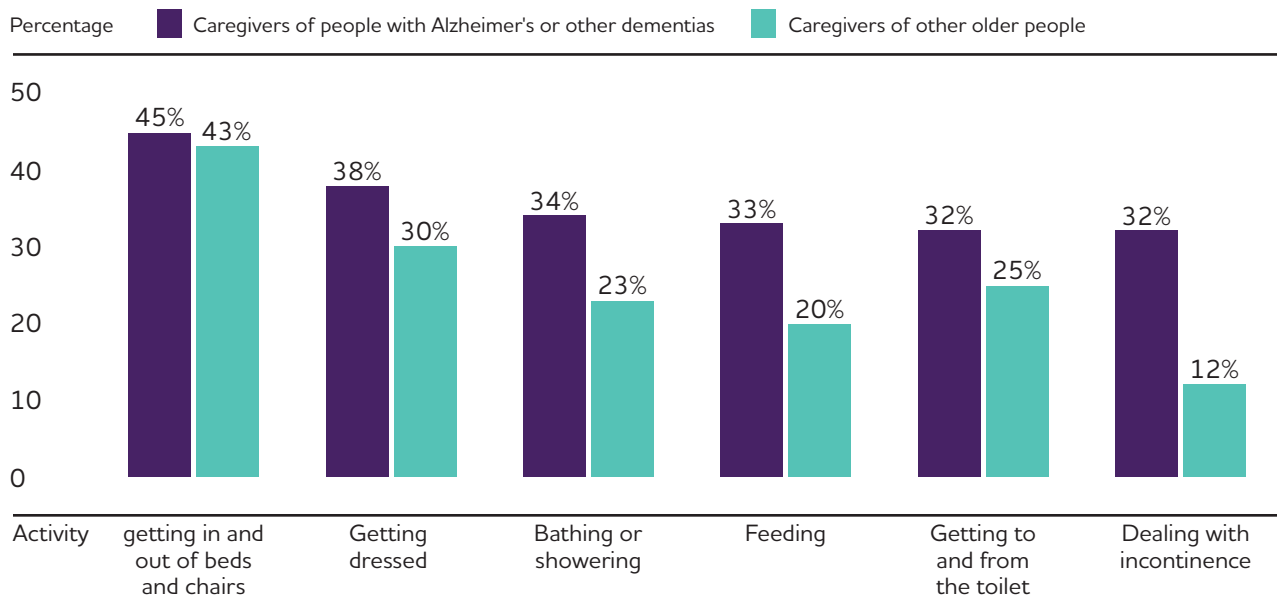
Maximize the availability of medical, preventive and home-based support services by promoting use of telemedicine and other technology that brings Alzheimer's expertise to sites that lack specialized skills or advanced training. The Advisory Council should examine and identify funding streams and ways to expand utilization of telehealth to develop and facilitate the full spectrum of telehealth services to rural communities, including training for providers in rural areas.

## Family Caregiver

### Care for the Family Caregiver

Alzheimer's and other dementias rob individuals over time of their ability to process what is going on around them and manage the day-to-day *Activities of Daily Living* (ADLs) which are both essential and routine aspects of self-care. The six essential ADLs include the ability to be able to independently eat, dress, walk or transfer from one position to another, bathe, toilet, and maintaining bowel and bladder continence. Although there are many circumstances family care for loved ones in a home setting, adding Alzheimer's and other dementias to the mix can increase the intensity of care.

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



Created from data from the National Alliance for Caregiving and AARP<sup>286</sup>

The person diagnosed with Alzheimer's is often confused over what is being asked of them in assisting with their daily care. This creates a unique set of challenges for family caregivers. For some, additional co-morbidities such as Parkinson's disease, create neurological and physical challenges that add to required care. There is eventually confusion about their relationships with life-long family members whom they may not recognize someday. All these things come together to create enormous financial and logistical challenges for family members who are caring for their loved one in a home setting — challenges every day to do the best job they can. The fear, frustration, and heartbreak are palpable and the physical and emotional toll on primary family caregivers is often overwhelming.

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)	Higher Health Care Costs of Caregivers (in millions of dollars)*
Alabama	305	347	54,392	5200
Alaska	33	38	479	33
Arizona	339	386	4,883	198
Arkansas	178	203	2,560	119
California	1,621	1,846	23,337	1,109
Colorado	252	287	3,631	155
Connecticut	178	202	2,559	158
Delaware	55	62	786	50
District of Columbia	29	33	415	31
Florida	1,141	1,299	16,419	832
Georgia	533	607	7,678	317
Hawaii	65	74	941	43
Idaho	85	97	1,223	53
Illinois	588	670	8,471	440
Indiana	340	387	4,890	255
Iowa	136	155	1,961	101
Kansas	151	172	2,179	105
Kentucky	273	311	3,936	197
Louisiana	232	264	3,335	164

## Kansas Data

2019 Alzheimer's Disease Facts and Figures, Caregiving section, page 36

**170 million hours  
OF UNPAID CARE**

**\$2.17 billion  
IN ECONOMIC VALUE OF UNPAID CARE**

**\$105 million in higher health care costs  
OF CAREGIVERS FOR KANSAS, 2018**

While understanding there are those with younger onset Alzheimer's, the majority are diagnosed in the sixth or seventh decade of life. This means the primary caregiving is often defined as:

- Approximately two-thirds of dementia caregivers are women.
- About one in three caregivers (34 percent) are age 65 or older.
- More than 60 percent of caregivers are married, living with a partner or in a long-term relationship.
- Most caregivers (66 percent) live with the person with dementia in the community.
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for children under age 18.

- Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. Nearly half of all caregivers (48 percent) who provide help to older adults do so for someone with Alzheimer's or another dementia.
- The total lifetime cost of care for someone with dementia was estimated at \$350,174 in 2018 dollars. The costs associated with family care make up 70 percent of lifetime dementia care costs. These estimates may underestimate the impact of a relative's dementia on family caregivers' health and workplace productivity.

*2019 Alzheimer's Disease Facts and Figures, Caregiving section, page 31*

The primary caregiver is usually a family member and often a spouse. Consequently, they may become more vulnerable to depression and illness, especially considering the years of care ahead of them. They can be so absorbed in caring for the person with dementia that they become neglectful of self-care. Outside support systems must be vigilant in monitoring and supporting the health of the primary caregiver. Primary and secondary caregivers may also be daughters and sons, grandchildren and, nieces and nephews most of whom will be working, and some are still raising children. There is the challenge of the day-to-day care for the declining primary caregiver as well as seeing after their ongoing medical care. Family caregivers can also be vulnerable to losing their sick leave or vacation time from jobs when they need to respond to increasing care needs. Not unlike a spouse, they will be caught between their job demands and the needs of their own families. They too may neglect their own health. It is not just about physical health; it is also about the impact on mental health as well.

### Family Caregivers

**57%**

of family caregivers of people with Alzheimer's and other dementias in the community had provided care for 4 or more years.



**63%**

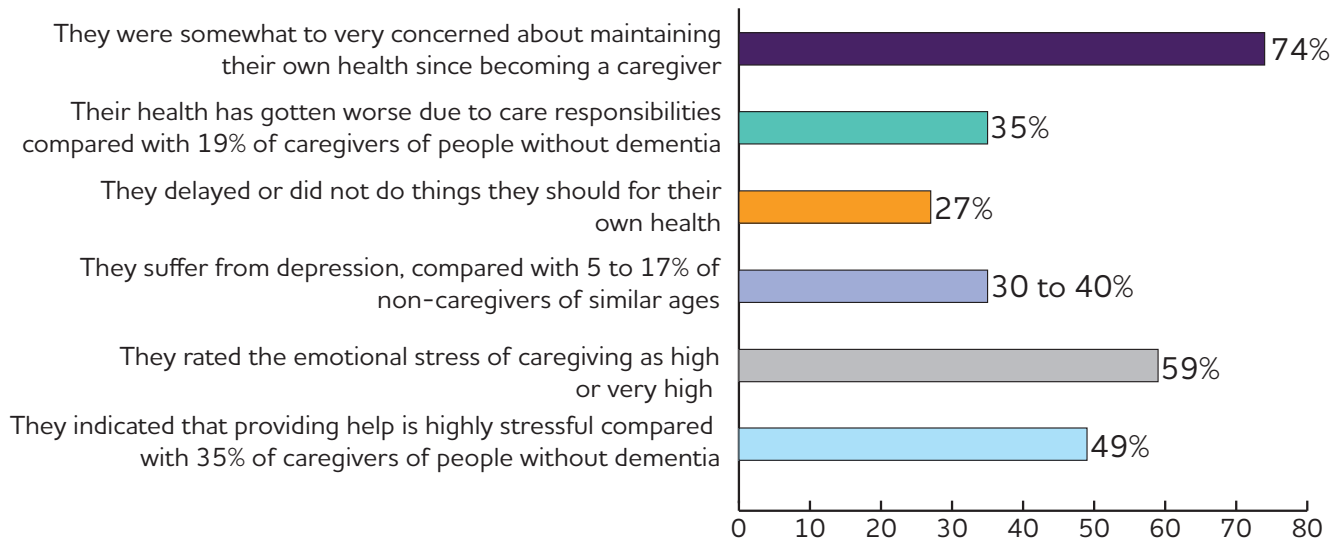
of Alzheimer's caregivers expect to have care responsibilities for the next 5 years compared with less than half of caregivers of people without dementia.

*2019 Alzheimer's Disease Facts and Figures, Caregiving section, page 33*

- Apart from its long duration, the immediate demands of caregiving are also time intensive. Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia, with over half providing more than 21 hours of care per week.



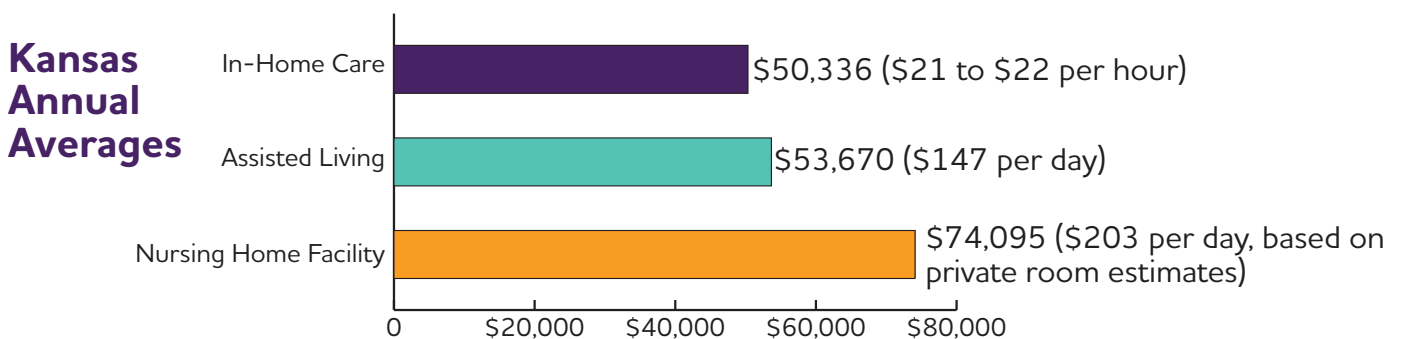
## Caregivers of people with Alzheimer's and other dementias reported that:



2019 Alzheimer's Disease Facts and Figures, Caregiving section, page 35

2019 Alzheimer's Disease Facts and Figures, Caregiving section, page 34

The cost of care increases as the person with Alzheimer's and other dementias requires greater support or possible long-term care placement. Most families strive to keep their declining family member in a home setting for as long as possible because the alternative cost of private duty care in the home, assisted living or skilled nursing home care can be too expensive. Over time, savings, insurance coverage, and other financial resources can become exhausted.



## Current Services

The committee's research shows there are isolated resources and services that can be helpful, but to only certain populations or communities. We would prefer to see more comprehensive supports for all Kansans.

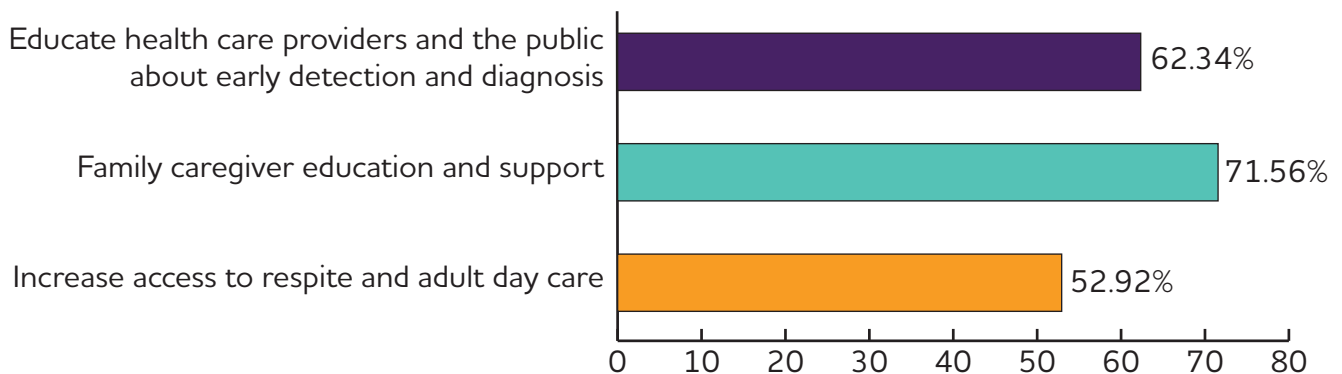
- Caregiver support groups and services
  - The Veteran's Administration Caregiver Support program offers a variety of programs for the caregiver of the veteran with Alzheimer's disease who is enrolled in the VA.

*"We are living in a state whose aging population is on the rise while the younger populations are on the decline. To say the time is now and the future picture is critical understates what we face."*

Carol – Topeka, KS

- Caregiver Support Services are offered through each Area Agency on Aging to assist caregivers.
- Caregiver Support groups are offered through the Kansas chapters of the Alzheimer's Association and other agencies and organizations to assist caregivers.

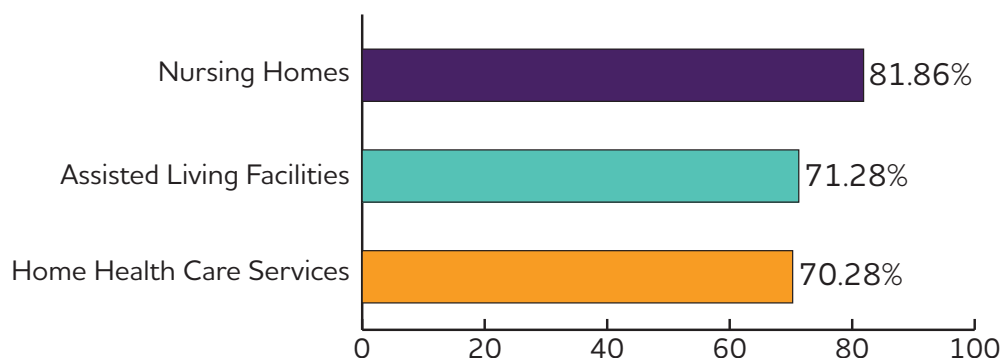
***In your opinion, what are the three most critical issues that Kansas should address in the next five years?***



**43.86%**

***of caregivers did not receive any regular training or updates on caring for someone with Alzheimer's and other dementias at home***

***What care resources are available to you in your county?***



## Recommendations

### 1. Family Caregiver Training Program / Incentives

Family caregivers are often overwhelmed, trying to figure out new circumstances and information fast. Committed primary caregivers have the heart and desire to serve the ones they love, but often are unaware of the logistical or technical skills needed to manage care that certified and state licensed professionals train for. Often, we send willing family members home with a naïve notion that they can manage all the expected caregiving responsibilities when what happens is, we set them up to fail.

Community and paid resources are critical components of care, but families often underestimate how much assistance they will need or what is covered under Medicare or other limited healthcare plans.

The costs of professional care and lack of resources across the state create unique challenges. There are not enough resources and the need for more confident family caregivers will heighten the priority to better train families.

#### Family Caregiving Training

- Creating skilled learning opportunities, not unlike a CNA or healthcare professional course, is important to equip family caregivers to better care for their loved one in a home setting for a longer period. Various forms of learning are essential to giving committed family caregivers valuable knowledge prior to and during the process of learning how to meet the ongoing needs of the person they are caring for in a home environment.
  - Online learning including to-do videos.
  - Online tools library that include forms and tips for topics like medication management, or home safety signage.
  - Webinar courses that help with more interactive learning and ongoing skills training.
  - Live skilled training with professional healthcare works to learn hands on skills and observable competencies.
  - Hotline or FaceTime support to ask non-emergent questions.

#### Benefits

- Reduce risk of individual or caregiver injuries.
- Reduce risk of re-hospitalization and financial penalties.
- Reduce risk of increased mental costs and Medicare increases.

- Increase skilled care population by empowering families to be more successful at home.
- Prolong unnecessary and expensive care until it is truly needed.

### Institutional Support

Universities and schools that provide CNA or nursing courses are uniquely equipped to implement family caregiver training programs.

- They have facilities and labs with standard equipment for training basic caregiving skills, i.e., transfers, bathing, incontinence care, in various environments and situations.
- They have qualified instructors that clearly understand the benefits of knowing the basics when caring for a loved one at home.
- They have students that could be utilized for training family members as part of their own training, proving the best way to exhibit learning is when you teach someone else.

### Financial Assistance

- Create financial support or incentives for universities and schools to offer low cost or free family caregiver training programs.
- Create financial support or incentives for area hospitals and healthcare partners to support training program with staff expertise and scholarship support for participants.
- If training program met certain state guidelines, create a tax incentive for family caregivers once they complete the course successfully and obtained a certificate of completion.

A state-endorsed program and incentives would expand caregiver's knowledge and skillsets for this very special and challenging circumstance.

2. Expand caregiver support groups and services with state funding. Expansion of Alzheimer's Association current resources. One of the best examples of comprehensive community and family support is the Alzheimer's Association. The Heart of America chapter covers the upper northwest corner of the state including Kansas City. The Central and Western Kansas chapter covers the rest of the state. This subcommittee would recommend an exploration of a partnership between the State of Kansas and these agencies to expand access to support groups and volunteer training to some of the most untouched areas of the state.
3. Increased access to free or affordable legal services and financial planning resources.

4. Expanding the PACE Program to non-Medicaid qualified recipients / waivers, including younger onset and those over 65.
5. Statement of support for the state implementation of the federal BOLD Act law.
  - This subcommittee recommends the state support and exploration of how the federal BOLD Act law would bring additional resources to the state. The goal is to identify Alzheimer's as a "public health issue," specifically, meeting the three-point criteria: (1) the burden is large; (2) the impact is major; and (3) there are ways to intervene. The initiative would provide funding to state, local, and public health departments or other community entities to implement those interventions. This would bring training and resources to areas throughout the state, including most needed healthcare deserts like southwest Kansas and other smaller rural communities that have very little to support family caregiver support. (see Appendix BOLD Infrastructure for Alzheimer's Act).
6. Enlist and educate civic organization and faith communities as a resource for information and volunteer support for family caregivers.
7. Promote the Alzheimer's Association 24/7 Helpline at (800) 272-3900 to caregivers, public and private community partners.

## **Care for All With Dementia in Kansas**

### **Setting standards for dementia care providers and services in Kansas**

Caring for a person with Alzheimer's and other dementias is complex and multidimensional. This care is often provided by professional care providers in the community including (but not limited to) physicians, nurses, residential communities, and other allied health professionals. Individuals with dementia and their families trust that these professional providers meet appropriate quality standards in ensure the best quality care.

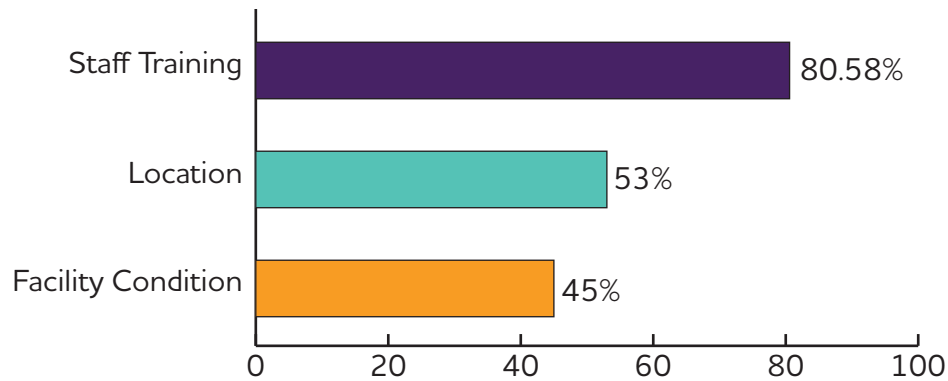
The Dementia Care working group of the Kansas State Alzheimer's Task Force is focused on developing, supporting, and promoting standards, education, training, and innovation to increase quality of life for those with dementia, help guide families through the dementia journey, and help providers set themselves apart by providing quality, evidence-based care that every person deserves. By creating a mutual dialogue between persons with dementia, their family members, oversight agencies, and professional care providers, Kansas will benefit from being a leader in providing safe, high quality, compassionate, and financially sustainable dementia care.

## Current Services

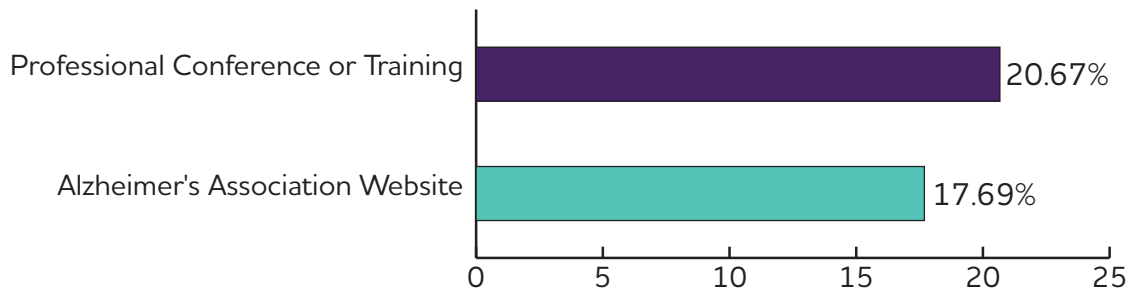
The committee's research shows a need for more consistent standards and creating centralized and sharable resources for all healthcare providers working with individuals diagnosed with Alzheimer's and other dementias, and their family and community.

- Kansas Department on Aging. Statutes and Regulations for the Licensure and Operation of Home Plus Facilities. Chapter 39—Mental Ill, incapacitated and Dependent Persons; Social Welfare. Article 9.—Adult Care Homes. Existing state regulations related to dementia care and education in HomePlus Facilities.
  - 39-923 (7) “Home plus” means any residence or facility caring for not more than 12 individuals not related within the third degree of relationship to the operator or owner by blood or marriage unless the resident in need of care is approved for placement by the secretary of the department of social and rehabilitation services, and who, due to functional impairment, needs personal care and may need supervised nursing care to compensate for activities of daily living limitations. The level of care provided residents shall be determined by preparation of the staff and rules and regulations developed by the department on aging. An adult care home may convert a portion of one wing of the facility to a not less than five-bed and not more than twelve-bed home plus facility provided that the home plus facility remains separate from the adult care home, and each facility must remain contiguous. Any home plus that provides care for more than eight individuals after the effective date of this act shall adjust staffing personnel and resources as necessary to meet residents' needs in order to maintain the current level of nursing care standards. Personnel of any home plus who provide services for residents with dementia shall be required to take annual dementia care training.
  - STAFF DEVELOPMENT. 26-42-103. Staff development. (a) The administrator or operator of each home plus shall ensure the provision of orientation to new employees and regular in-service education for all employees to ensure that the services provided assist residents to attain and maintain their individuality, autonomy, dignity, independence, and ability to make choices in a home environment. (c) If the home plus admits residents with dementia, the administrator or operator shall ensure the provision of staff education, at orientation and at least annually thereafter, on the treatment and appropriate response to persons who exhibit behaviors associated with dementia.

***When assessing care needs for a loved one that may need facility placement, which three are most important to you?***



***Where do you get information on dementia for your facility/practice?***



- High quality training drives the transformation of quality care. Research, as highlighted in the Alzheimer's Association Dementia Care Practice Recommendations shows that high-quality dementia care training can lead to an improvement in communication between caregivers and individuals living with dementia, a reduction in dementia-related behaviors and an increase in job satisfaction for staff.
- Through Alzheimer's Association curriculum review and essentiALZ certification, residential and community-based provider organizations have the opportunity to ensure their professional training programs reflect current evidence-based quality care practices outlined in the Dementia Care Practice Recommendations. Providers who train their staff with a training program recognized by the Alzheimer's Association are eligible to purchase the essentiALZ certification, an exam which tests knowledge of dementia care.

### **Statewide Physician and Primary Care Provider Education/Training Program**

Dementia care in Kansas is divided across sectors of care leading to challenges for the individual with dementia, their family members, and friends. This fragmentation often leads to delays in diagnosis, inadequate disease management, and extensive strain on individuals, families, clinicians, the health care system, and society.

Family physicians and other primary care providers (internal medicine physicians, ARNPs, PAs, etc.) are often the first point of contact with the health system for individuals with dementia. As such, they are ideally positioned to be involved with all aspects of care including prevention, the diagnostic process, and communication of the diagnosis to the individual, and post-diagnosis management. Many primary care providers, however, experience significant challenges in dementia care and often feel ill-prepared due to the complexity of dementia, lack of access to specialists (especially in rural and remote areas), insufficient knowledge of community-based resources, time constraints and challenges in coordinating patient and family needs.

The fear of unnecessary and costly over-regulation to care facilities and community healthcare providers like home health and hospice agencies, is a real fear. These recommendations are intended to create quality expectations in the support and care of individual's with Alzheimer's and other dementias, and their caregivers, family or otherwise. For this to happen in an equitable way between provider and consumer of services, all parties need a fair and equal voice in creating the care we want, can afford, and can effectively provider.

Although nursing homes, assisted living (including residential care and HomePlus licensed) communities may have memory care units/focus on the premises, dementia care is clearly different, requiring specialized tools and skills. Memory care is a distinct form of long-term care that specifically caters to patients, residents, clients with Alzheimer's disease, dementia and other types of cognitive problems.

The same can be said about in-home/community healthcare providers such as home health and hospice agencies. These services often have diagnoses specific programs. Guaranteeing quality dementia care based on recognized best practices and quality outcomes is important to the patients and families being served through these important services.

## Essential Needs

- Kansans with dementia have complex care needs. It is imperative that primary care providers understand the ongoing medical management needs of persons living with dementia and their loved ones to maximize quality of life, proactively plan for anticipated needs, and be as well prepared as possible for health crises that may occur (Austrom et al., 2018). Primary care providers are often the gatekeepers for key aspects of care for people with dementia. For most, it is the primary care practitioners that opens the door to information, support, and planning.
- Access to dementia capable care and support is inconsistent throughout Kansas with significant limitations in rural counties. Kansas needs a comprehensive and consistent strategy so that care of those with dementia is focused on preparation, or even prevention, as opposed to crisis and unmet needs.

## Recommendations

1. Promote the NIA-designated University of Kansas Alzheimer's Disease Research Center as the key source for community physicians to support diagnosis and management of complex cases.
2. Establish a statewide collaborative network consisting of education, training, and direct in-clinic support for primary care providers by fully funding the University of Kansas Alzheimer's Disease Research Center's Community Care Network (MyAlliance for Cognitive Health).
3. Develop protocols or utilize preexisting, evidence-based protocols and best practice standards for care of persons with Alzheimer's and other dementias, and use these in the training of physicians, nurses, other primary care providers, and allied health professionals statewide.
4. Promote the Dementia Care Practice Recommendations (Fazio, S., Pace, D., Maslow, K., Zimmerman, S., & Kallmyer, B. (Eds.). (2018), *The Gerontologist*, 58(S1)) in partnership with interested stakeholders (Alzheimer's Association, Kansas Academy of Family Physicians, KDADS, etc.) across the state to physicians, primary care providers, hospitals, and medical offices. <https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf>
5. Develop a pilot project to utilize and assess the effectiveness, efficiency, and reimbursable options for telehealth services in Kansas rural populations, thus creating a care ecosystem (<https://memory.ucsf.edu/research-trials/professional/care-ecosystem>) consisting of personalized, cost-efficient care for persons with dementia and their caregivers.
6. Kansas should work with the Alzheimer's Association, the KU Alzheimer's Disease Research Center, and other appropriate organizations to develop a multidisciplinary "toolbox" for physicians, other medical professionals, and allied health professionals. This toolbox would be easily accessible and available free of charge on relevant websites (KDADS, KDHE, Kansas Academy of Family Physicians, Kansas Dental Association, Kansas State Nurses Association, Kansas Behavioral Sciences Regulatory Board, etc.).
7. Establish Community Dementia Support Navigators based in all 11 Area Agency on Aging offices throughout the state to assist families and communities in care coordination of key resources and services.
8. Promote "Dementia Capable" certified facilities and providers.
9. Pilot the development of an accredited Geriatric Emergency Department.

10. Establish a subcommittee of the Advisory Council. This group should include the following specifics in order to guarantee understanding of the provider industries, technical aspects, reasonable expectations, and qualifiers of best practices.
  - 2 representatives of the Long-term care / Nursing home industry.
  - 2 representatives of the Assisted Living industry.
  - 2 representatives of the HomePlus industry.
  - A representative from the Home Health and Hospice Industry.
  - A representative from a patient advocacy organization.
  - A representative from the facility trade groups, i.e. KHCA/KCAL or Leading Age.The above or additional recommendations should include various disciplines, including:
  - Nursing
  - Therapy
  - Social Work
  - Activities Director
  - Administrator / Operators
  - Medical Directors or Primary Care Practitioners
11. Establish key standards for various care facility providers that promote common and reasonable best practices when a person with dementia is placed in facility care.
  - Federal Licensures, i.e., skilled nursing homes and long-term care facilities.
  - State Licensures, i.e., assisted living, residential care, and HomePlus facilities.
12. Establish key healthcare provider standards for various agencies that promote common and reasonable best practices when a person with dementia is on these services.
  - Home health
  - Hospice
  - DME (Durable Medical Equipment) services providing equipment, i.e., O2, wheeler chairs, hospital beds, etc.
13. Create support resources for providers that have met standards of certification. “Membership comes with benefits.”

- Registry on suggested KDADS site (per Public Awareness subcommittee recommendation) of “Dementia Capable” certified facilities and providers for consumers to easily access. This would also provide a resource for referral agencies to guide their clients, such as Area Agencies on Aging, hospital networks, general public searching internet, and other senior driven resource brokers.
  - State of Kansas to make request for Medicare.gov / facility locator site indicate if a facility is certified “dementia capable.”
  - Training and online resource center for facilities and providers. **(See Kansas TRAIN as an example. <https://www.train.org/ks/welcome>)**
  - Offer incentives or discounts for partnering on Dementia Capable certification process.
  - Provide collateral resources for dementia care providers in order to assist and give them all of the necessary tools to deliver the highest quality of care. These resources should include relevant forms, guidelines/best practices, helpful links, and training recommendations. For reference, see Kansas TRAIN under the resource tab (<https://www.train.org/ks/search?type=document>), and Sunflower Health Plans Provider Resource tab (<https://www.sunflowerhealthplan.com/providers.html>).
14. Promote the NIA-designated University of Kansas Alzheimer’s Disease Research Center as the key source for community physicians to support diagnosis and management of complex cases.
  15. Establish a statewide collaborative network consisting of education, training, and direct in-clinic support for primary care providers by fully funding the University of Kansas Alzheimer’s Disease Research Center’s Community Care Network (MyAlliance for Cognitive Health).
  16. Develop protocols or utilize preexisting, evidence-based protocols and best practice standards for care of persons with Alzheimer’s and other dementias, and use these in the training of physicians, nurses, other primary care providers, and allied health professionals statewide.
  17. Promote the Dementia Care Practice Recommendations (Fazio, S., Pace, D., Maslow, K., Zimmerman, S., & Kallmyer, B. (Eds.). (2018), *The Gerontologist*, 58(S1)) in partnership with interested stakeholders (Alzheimer’s Association, Kansas Academy of Family Physicians, KDADS, etc.) across the state to physicians, primary care providers, hospitals, and medical offices. <https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf>

18. Develop a pilot project to utilize and assess the effectiveness, efficiency, and reimbursable options for telehealth services in Kansas rural populations, thus creating a care ecosystem (<https://memory.ucsf.edu/research-trials/professional/care-ecosystem>) consisting of personalized, cost-efficient care for persons with dementia and their caregivers.
19. Kansas should work with the Alzheimer's Association, the KU Alzheimer's Disease Research Center, and other appropriate organizations to develop a multidisciplinary "toolbox" for physicians, other medical professionals, and allied health professionals. This toolbox would be easily accessible and available free of charge on relevant websites (KDADS, KDHE, Kansas Academy of Family Physicians, Kansas Dental Association, Kansas State Nurses Association, Kansas Behavioral Sciences Regulatory Board, etc.).
20. Establish Community Dementia Support Navigators based in all 11 Area Agency on Aging offices throughout the state to assist families and communities in care coordination of key resources and services.
21. Promote "Dementia Capable" certified facilities and providers.
22. Navigate other state programs and overcome barriers.

## Glossary

### A

**Activities of Daily Living (ADLs)** – a series of basic activities performed by individuals on a daily basis necessary for independent living at home or in the community such as eating, bathing, and dressing.

**Adult day care** – used to relieve the caregiver of his or her duties for the day while ensuring that the care recipient will still receive the proper care in a safe, friendly environment.

**Adult Protective Service** – responds to reports of abuse, neglect or exploitation of adults.

### B

**Behavioral Risk Factor Surveillance System (BRFSS)** – is the nation's premier system of health- related telephone surveys that collect data about U.S. residents regarding their health-related risk behaviors, chronic health conditions and use of preventive services. It is designed by the Centers of Disease Control and Prevention. It is conducted in all 50 states and U.S. territories. The Kansas Department of Health and Environment conducts the survey in Kansas.

### C

**Clinical trials** – Clinical trials are research studies that explore whether a medical strategy, treatment or device is safe and effective for humans. Without clinical trials with human volunteers, there can be no better treatments, no prevention and no cure for Alzheimer's disease.

**Cognitive decline** – Cognitive decline refers to a progressive loss of cognition or mental abilities.

**Co-morbidities** – the simultaneous presence of two or more chronic diseases or conditions in a patient.

**Continuum of care** – concept involving an integrated system of care that guides and tracks patients over time through a comprehensive array of health services spanning all levels of intensity of care.

## D

**Delirium** – Delirium is a serious disturbance in mental abilities that results in confused thinking and reduced awareness of the environment. The start of delirium is usually rapid within a few hours or a few days. Delirium may have a single cause or more than one cause.

**Dementia capable care** – a high quality individualized, coordinated and integrated system of care to meet the medical, physical, psycho-social and spiritual needs of a person with Alzheimer's and other dementias.

**Dementia friendly communities** – a place or culture in which people with dementia and their caregivers are empowered, supported and included in society, understand their rights and recognize their full potential.

## E

**EssentiALZ** – Developed by the Alzheimer's Association in accordance with the Dementia Care Practice Recommendations, essentiALZ® certification is an online exam that tests care providers' knowledge of evidence-based and person-centered care for individuals living with dementia.

## F

**FAST** – Financial Abuse Specialist Team – a specialized fraud unit, working with concerned members of the community, to address the growing problem of financial abuse of the elderly.

## G

**Geriatricians** – medical doctors who specialize in treating older adults.

## H

**Home Plus** – residence of facility caring for not more than 12 individuals who need personal care or supervised nursing care to help with limitations in activities of daily living.

## K

**Kansas Department for Aging and Disability Services (KDADS)** – state agency that provides services to older adults and persons with disabilities.

**Kansas Department of Health and Environment (KDHE)** – state agency responsible for Kansas' public health system.

**Kansas Health Care Association** – statewide non-profit association that represents over 260 long-term care providers.

## M

**Minimum data set (MDS)** – part of the federally mandated process for clinical assessment of all residents in Medicare and Medicaid certified nursing homes.

**Models of care** – broadly defines the way health services are organized and delivered.

## N

**National Institute of Aging (NIA)** – federal agency that leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. NIA is the primary federal agency supporting and conducting Alzheimer's disease research.

**National Institutes of Health (NIH)** – federal agency that is part of the U.S. Department of Health and Human Services. NIH is the largest biomedical research agency in the world.

**Neurodegenerative** – resulting in or characterized by degeneration of the nervous system, especially the neurons in the brain.

**Neurologists** – medical doctor who treats disorders that affect the brain, spinal cord, and nerves.

**Neuropsychologist** – psychologist who specializes in understanding the relationship between the physical brain and behavior.

## O

**Older Americans Act** – passed in 1965 by Congress. Provides funding to the states for the delivery of social and nutrition services to those 60 and older and their caregivers.

## P

**Prevalence** – proportion of a population who have a specific characteristic in a given time period.

## R

**Respite care** – provides short-term relief for primary caregivers. It can be arranged for just an afternoon or for several days or weeks. Care can be provided at home, in a healthcare facility, or at an adult day center.

## S

**Senior Care Act** – established by the Kansas Legislature to assist older Kansans who have functional limitations in self-care and independent living, but who are able to reside in a community based residence if some services are provided.

**Senior Safe Act** – allows banks and other financial providers to report fiduciary abuse. The law extends immunity from liability to certain trained individuals and their employing financial institution who, in good faith and with reasonable care, disclose suspected exploitation of a senior citizen to a regulatory or law enforcement agency.

**Siloed** – kept in isolation in a way that hinders communication and cooperation.

**Skilled facilities** – a nursing home recognized by the Medicare and Medicaid systems as meeting long term care needs for individuals who have the potential to function independently after a limited period of care. A multidisciplinary team guides health care and rehabilitative services, including skilled nursing care.

**Support group** – Support groups are a group of individuals who have common experiences or concerns who provide each other with encouragement, comfort and advice.

## T

**Transition of care** – refers to changing the setting in which a person is being treated. For example, if a person is transferred from inpatient hospital care to a nursing home after their hospital stay, then that person has experienced transition of care between two different facilities.

**Transportable physician order for patient preferences (TPOPP)** – designed to ensure that seriously ill or frail patients can choose the treatments they want or do not want and that their wishes are documented and honored.

**TrialMatch** – free, easy-to-use clinical studies matching service that generates customized lists of studies based on user-provided information.

## U

**U. S. Department of Health and Human Services** – federal agency that provides for health and human services and fostering advances in medicine, public health, and social services.

## **Appendix A**

### **Members of the Kansas Alzheimer's Disease Task Force**

Cindy Schmidt – Person with the disease

Allen Schmidt – Caregiver for Cindy Schmidt

Gina Long – Caregiver for her mother

Rita Ortolani – Caregiver for her husband

Robert Miller – LMSW, CDP, VP of Company Development with Comfort Care Homes

Sarah Duggan – Community Relations Director for Meadowlark Hills Assisted Living

Dr. Joseph Schlageck – Medical care provider

Janie Krull – APRN, FNP, CCRC Clinical Research Manager with  
Ascension Via Christi Hospital

Dr. Stephen Benson – PSY.D, P.A. specializes in Geriatric Care

Randy Clinkscales – Elder law attorney

Jamie Gideon – Chair and Director of Public Policy for the Alzheimer's Association

Carol Jolly – member of the Silver Hair Legislature

Rob Razo – Behavioral Health/Crisis Intervention Officer with the Topeka Police Department

Rep. Eileen Horn – State representative appointed by the Minority Leader of the Kansas  
House of Representatives

Annette Graham – Executive Director of the Central Plains Area Agency on Aging,  
appointed by Minority Leader of the Kansas Senate

## Appendix B

### Causes of Dementia and Associated Characteristics

#### Alzheimer's Disease

Most common cause of dementia; accounts for an estimated 60 percent to 80 percent of cases. Autopsy studies show that about half of these cases involve solely Alzheimer's pathology; many of the remaining cases have evidence of additional pathologic changes related to other dementias. This is called mixed pathology, and if recognized during life is called mixed dementia. Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioral changes and, ultimately, difficulty speaking, swallowing and walking. Revised guidelines for diagnosing Alzheimer's were proposed and published in 2011. They recommend that Alzheimer's be considered a slowly progressive brain disease that begins well before clinical symptoms emerge. The hallmark pathologies of Alzheimer's are the progressive accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are eventually accompanied by the damage and death of neurons.

#### Vascular Dementia

The brain changes of vascular dementia are found in about 40 percent of brains from individuals with dementia. About 10 percent of brains from individuals with dementia show evidence of vascular dementia alone. However, it is very common as a mixed pathology in older individuals with Alzheimer's dementia, about 50 percent of whom have pathologic evidence of infarcts (silent strokes). Impaired judgment or impaired ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's. In addition to changes in cognition, people with vascular dementia can have difficulty with motor function, especially slow gait and poor balance. Vascular dementia occurs most commonly from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.

In the past, evidence of vascular dementia was used to exclude a diagnosis of Alzheimer's (and vice versa). That practice is no longer considered consistent with the pathologic evidence, which shows the brain changes of Alzheimer's and vascular dementia commonly coexist. When there is clinical evidence of two or more causes of dementia, the individual is considered to have mixed dementia.

## **Dementia with Lewy Bodies (DLB)**

People with DLB have some of the symptoms common in Alzheimer's but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations, and slowness, gait imbalance or other parkinsonian movement features. These features, as well as early visuospatial impairment, may occur in the absence of significant memory impairment.

Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease (PD), in which it is accompanied by severe neuronal loss in a part of the brain called the substantia nigra. While people with DLB and PD both have Lewy bodies, the onset of the disease is marked by motor impairment in PD and cognitive impairment in DLB.

The brain changes of DLB alone can cause dementia, but very commonly people with DLB have coexisting Alzheimer's pathology. In people with both DLB and Alzheimer's pathology, symptoms of both diseases may emerge and lead to some confusion in diagnosis. Vascular dementia can also coexist and contribute to the dementia. When evidence of more than one dementia is recognized during life, the individual is said to have mixed dementia.

## **Mixed Dementia**

Characterized by the hallmark abnormalities of more than one cause of dementia — most commonly Alzheimer's combined with vascular dementia, followed by Alzheimer's with DLB, and Alzheimer's with vascular dementia and DLB. Vascular dementia with DLB is much less common.

Recent studies suggest that mixed dementia is more common than previously recognized, with about half of older people with dementia having pathologic evidence of more than one cause of dementia. Recent studies also show that the likelihood of having mixed dementia increases with age and is highest in the oldest-old (people age 85 or older).

## **Frontotemporal Lobar Degeneration (FTLD)**

Includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.

Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease.

Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein).

The symptoms of FTLD may occur in those age 65 years and older, similar to Alzheimer's, but most people with FTLD develop symptoms at a younger age. About 60 percent of people with FTLD are ages 45 to 60. FTLD accounts for about 10 percent of dementia cases.

### **Parkinson's Disease (PD)**

Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. In PD, alpha-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine. The incidence of PD is about one-tenth that of Alzheimer's.

As PD progresses, it often results in dementia secondary to the accumulation of Lewy bodies in the cortex (similar to DLB) or the accumulation of beta-amyloid clumps and tau tangles (similar to Alzheimer's).

### **Creutzfeldt-Jakob Disease**

This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes. Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction. May be hereditary (caused by a gene that runs in one's family), sporadic (unknown cause) or caused by a known prion infection. A specific form called variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.

### **Normal Pressure Hydrocephalus**

Symptoms include difficulty walking, memory loss and inability to control urination. Accounts for less than 5 percent of dementia cases. Caused by impaired reabsorption of cerebrospinal fluid and the consequent buildup of fluid in the brain, increasing pressure in the brain.

People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

*Alzheimer's Association. 2018 Alzheimer's Disease Facts and Figures. Alzheimer's Dementia 2018;14(3):367-429*

## Appendix C — Executive Order 19-08

### STATE OF KANSAS

CAPITOL BUILDING, ROOM 241 SOUTH  
TOPEKA, KS 66612



PHONE: (785) 296-3232  
GOVERNOR.KANSAS.GOV

GOVERNOR LAURA KELLY

#### EXECUTIVE ORDER NO. 19-08

Establishing the Kansas Alzheimer's Disease Task Force

**WHEREAS**, more than 54,000 Kansans suffer from Alzheimer's, and that number is estimated to more than triple by the year 2050; and

**WHEREAS**, nearly one out of every three seniors who die each year suffer from some form of dementia; and

**WHEREAS**, Alzheimer's is a serious disease that affects not only those who have it, but also their families and 151,000 caregivers in Kansas; and

**WHEREAS**, the severity of this health crisis necessitates the implementation of a statewide response plan; and

**WHEREAS**, this health crisis has a significant fiscal impact on the State of Kansas, which is estimated to keep increasing, currently costing \$441 million in Medicaid alone each year; and

**WHEREAS**, Alzheimer's and other forms of dementia negatively impact the health and quality of life of Kansans; and

**WHEREAS**, in 2018 Governor Colyer created an Alzheimer's Disease Plan task force that made significant progress.

**NOW THEREFORE**, pursuant to the authority vested in me as Governor of the State of Kansas, I hereby establish the Kansas Alzheimer's Disease Task Force ("Task Force"):

1. Membership of the "Task Force" shall be comprised of the following members:
  - a. One member appointed by the Speaker of the House;
  - b. One member appointed by the House Majority Leader;
  - c. One member appointed by the Minority Leader of the House;
  - d. One member appointed by the Senate President;
  - e. One member appointed by the Senate Majority Leader;
  - f. One member appointed by the Minority Leader of the Senate;
  - g. At least one person with Alzheimer's disease;

- h. At least one caregiver of a person with Alzheimer's disease;
  - i. A representative of the nursing facility industry;
  - j. A representative of the assisted living industry;
  - k. A representative of the in-home care/hospice industry;
  - l. A representative of the medical care provider community;
  - m. An Alzheimer's disease researcher;
  - n. A psychologist who specializes in geriatric care;
  - o. An elder law attorney;
  - p. A representative of the Alzheimer's Association;
  - q. A representative of the Kansas Silver Haired Legislature; and
  - r. A representative from the law enforcement community.
2. Research, data, administrative support, and guidance from the following agencies: Kansas Department of Labor, Kansas Department of Commerce, Kansas Department for Aging and Disability Services, and the Kansas Department of Health and Environment. The Kansas Department for Aging and Disability Services shall be primarily responsible for and take the lead in providing such support.
  3. The Governor shall select one member of the Task Force to serve as chair.
  4. Other members with relevant experience may be invited to join the Task Force by the Governor or Chair.
  5. The Task Force shall meet monthly or as needed, at the discretion of the Chair.
  6. Members of the Task Force shall not receive compensation, subsistence, allowance, or associated expenses. Officers or employees of state agencies who are appointed to the Task Force as part of their duties shall be authorized to participate on the Task Force and may claim subsistence, allowance, mileage, or associated expenses as permitted by law.
  7. It shall be the duty of the Task Force to:
    - a. Assess the current and future impact of Alzheimer's disease on residents of the State of Kansas;
    - b. Examine the existing industries, services, and resources addressing the needs of persons with Alzheimer's, their families, and caregivers; and
    - c. Develop a strategy to mobilize a state response to this public health crisis.

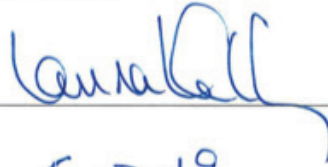
8. The Task Force shall also include an examination of the following in its assessment and recommendations:
  - a. Trends in Alzheimer's population and needs, including the changing population with dementia, including but not limited to:
    - i. State role in long-term care, family caregiver support, and assistance to persons with early-stage and early onset of Alzheimer's;
    - ii. Surveillance of persons with Alzheimer's disease for purposes of having proper estimates of the number of persons in the state with Alzheimer's disease; and
    - iii. The inappropriate use of antipsychotic medications to treat symptoms of dementia, which is a multi-faceted issue that touches every major area of our state's health care system, and comprehensive strategies to reduce this use.
  - b. Existing services, resources, and capability, including but not limited to the:
    - i. Type, cost, and availability of dementia services;
    - ii. Dementia-specific training requirements for long-term care staff;
    - iii. Quality care measures for long-term care facilities;
    - iv. Capacity of public safety and law enforcement to respond to persons with Alzheimer's;
    - v. Availability of home- and community-based resources for persons with Alzheimer's and respite care to assist families;
    - vi. Inventory of long-term care dementia care units;
    - vii. Adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's and related dementia;
    - viii. Assisted living residential options for persons with dementia; and
    - ix. State support of Alzheimer's research through Kansas universities and other resources.
  - c. Needed State policies or responses, including but not limited to directions for the provision of clear and coordinated services and supports to persons and families living with Alzheimer's and related disorders and strategies to address any identified gaps in services.
9. The Task Force is directed to hold public meetings and to utilize technological means, such as webcasts, to gather feedback on the recommendations from persons and families

affected by Alzheimer's disease and the general public. The Task Force shall be subject to the Kansas Open Records Act and the Kansas Open Meetings Act. Plans, reports, or recommendations of any nature adopted by the Task Force shall be considered advice to the Governor and Legislature, and shall not be construed as official policies, positions, or interpretations of laws, rules, or regulations by any department or agency of state government, nor shall any such department or agency be bound in any manner to consider such advice when conducting their regulatory affairs.

10. The Task Force is directed to submit a report of its finding and recommendations to the Legislature and Governor in the form of a Kansas Alzheimer's Disease Plan by January 13, 2020, or as appropriate during the intervening period.
11. The Task Force shall sunset upon delivery of the Kansas Alzheimer's Disease Plan to the Legislature and Governor. By further Executive Order, the Governor may reconvene the Task Force to update the plan in the future.

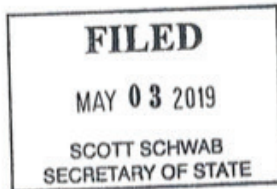
This document shall be filed with the Secretary of State as Executive Order No. 19-08. It shall become effective immediately and remain in force until rescinded.

BY THE GOVERNOR



DATED

5.2.19



Secretary of State



Assistant Secretary of State

## Appendix D – Bold Infrastructure for Alzheimer’s Act

### BOLD Infrastructure for Alzheimer's Act

What does the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406) do?

- The bipartisan BOLD Act was unanimously approved by the Senate and passed in the House of Representatives by a vote of 361-3. It was signed into law on December 31, 2018.
- As enacted, the BOLD Act:
  - Establishes Alzheimer's Centers of Excellence around the country to expand and promote innovative and effective Alzheimer's interventions.
  - Provides funding to state, local, and tribal public health departments to implement those interventions and to carry out the Public Health Road Map, including promoting early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.
  - Increase the analysis and timely reporting of data on cognitive decline and caregiving to inform future public health actions.

What are the next steps?

- The BOLD Act authorized \$100 million over five years to carry out the various public health activities addressing Alzheimer's and other dementias.
- Congress must fully fund the law by providing \$20 million in fiscal year 2020 for the CDC.

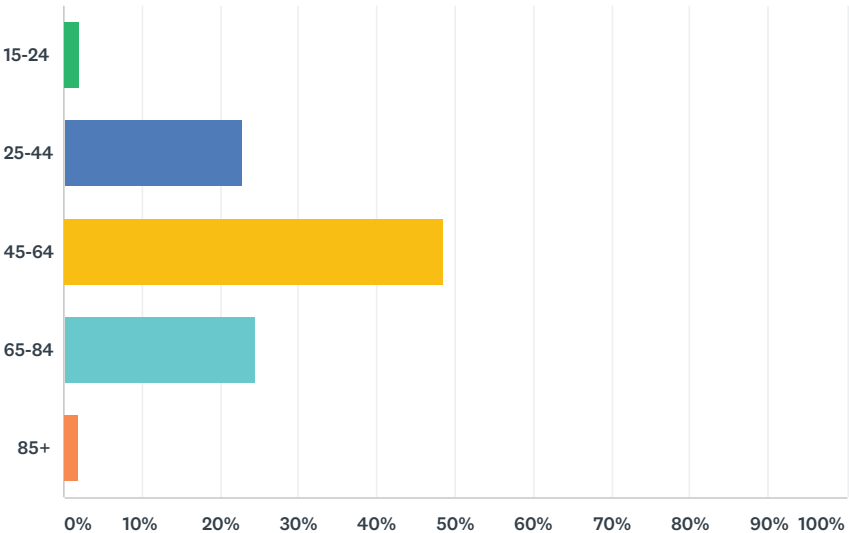
# Appendix E — Survey Results

2019 Alzheimer's Disease Task Force Survey

SurveyMonkey

## Q1 How old are you?

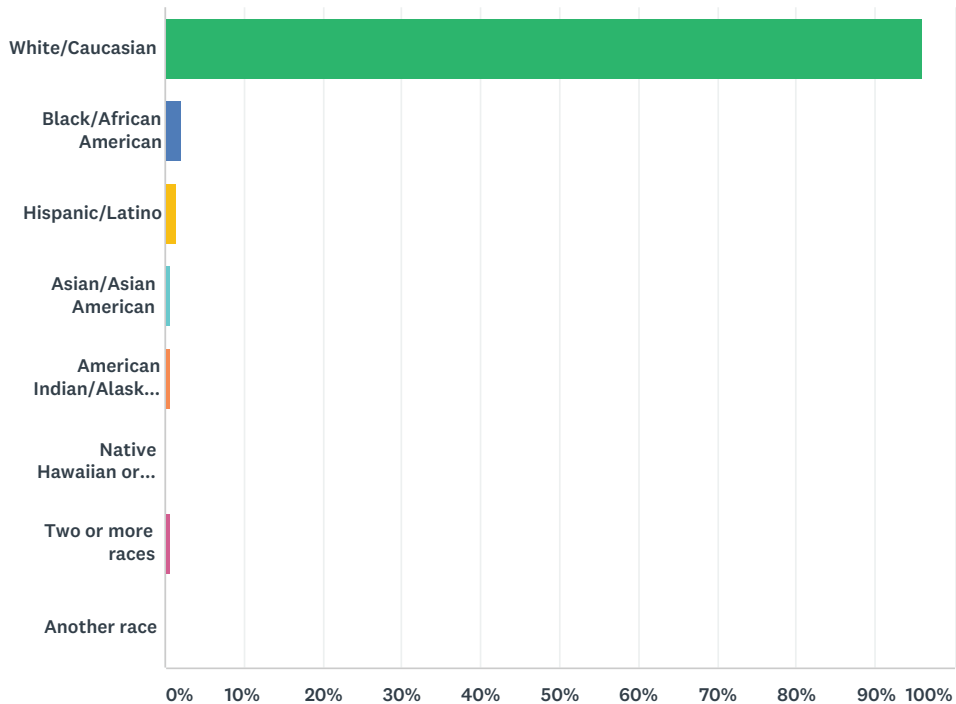
Answered: 1,048 Skipped: 18



ANSWER CHOICES	RESPONSES	
15-24	2.19%	23
25-44	22.90%	240
45-64	48.47%	508
65-84	24.52%	257
85+	1.91%	20
TOTAL		1,048

## Q2 What is your race or ethnicity? (Check all that apply)

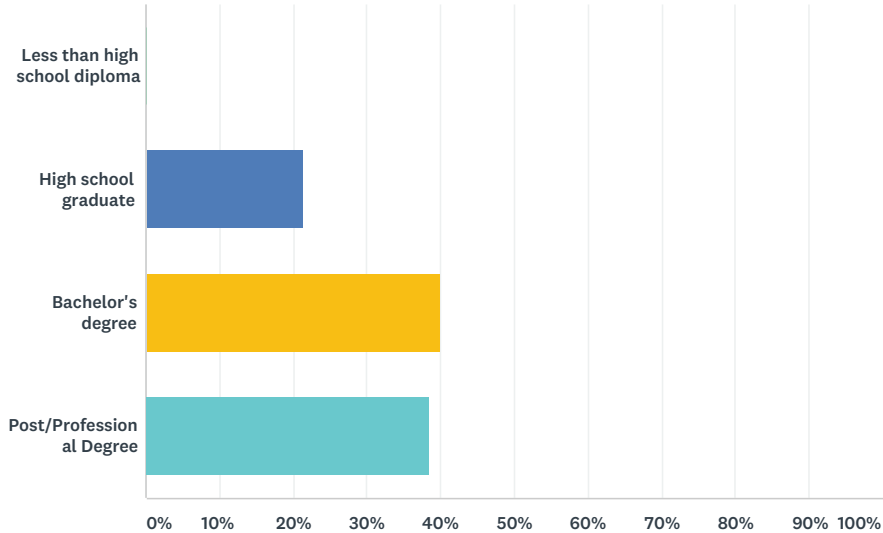
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ANSWER CHOICES	RESPONSES	
White/Caucasian	95.94%	1,015
Black/African American	2.08%	22
Hispanic/Latino	1.51%	16
Asian/Asian American	0.66%	7
American Indian/Alaska Native	0.66%	7
Native Hawaiian or other Pacific Islander	0.00%	0
Two or more races	0.66%	7
Another race	0.09%	1
Total Respondents: 1,058		

### Q3 What is the highest level of education you completed?

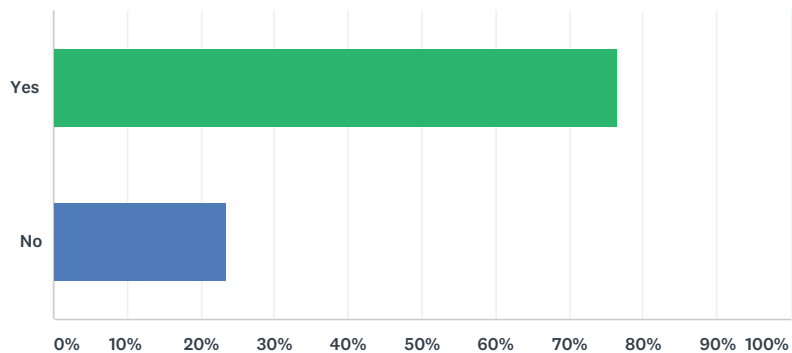
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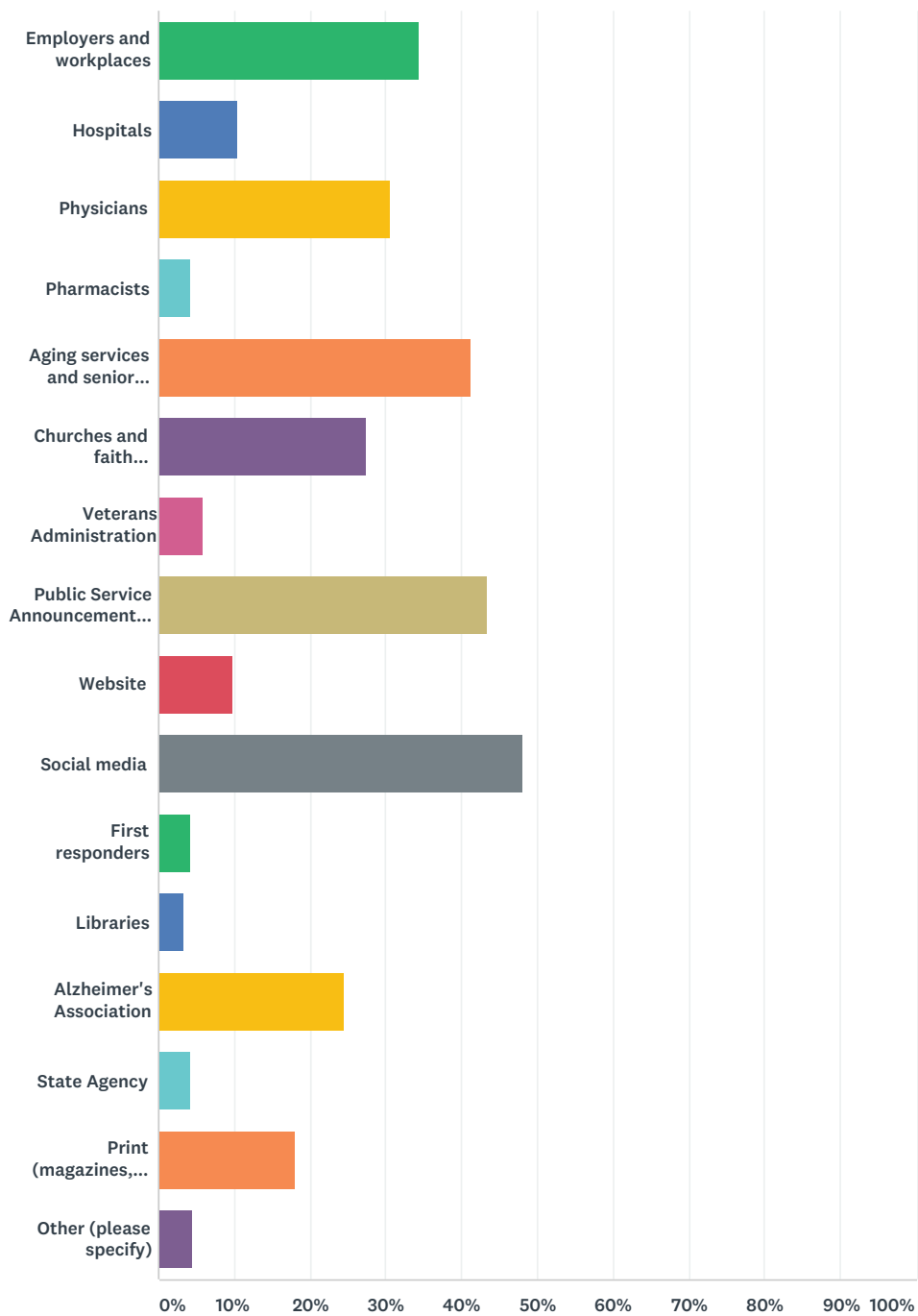
ANSWER CHOICES	RESPONSES	
Less than high school diploma	0.29%	3
High school graduate	21.24%	223
Bachelor's degree	40.00%	420
Post/Professional Degree	38.48%	404
TOTAL		1,050

### Q5 Do you live within city limits?

Answered: 1,047 Skipped: 19



ANSWER CHOICES	RESPONSES	
Yes	76.60%	802
No	23.40%	245
TOTAL		1,047

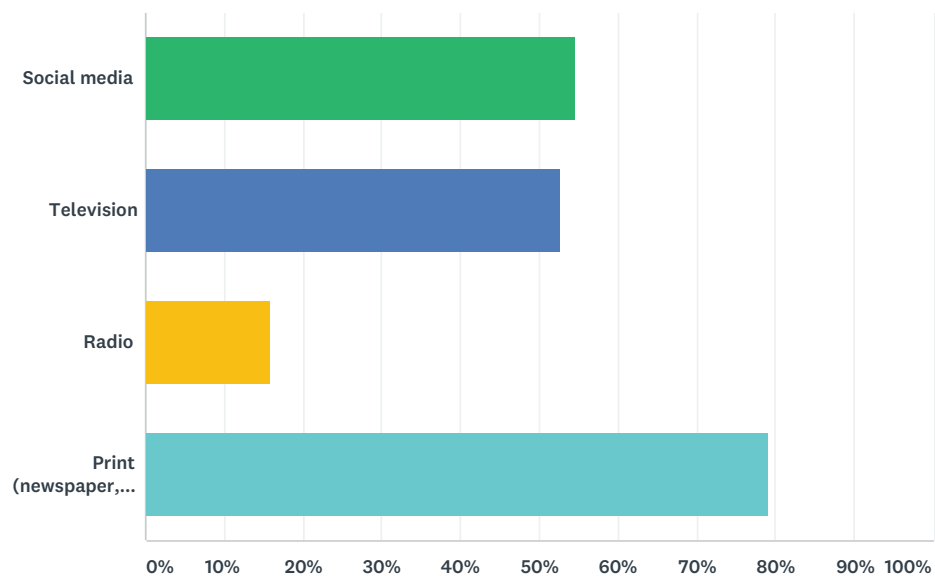


ANSWER CHOICES	RESPONSES	
Employers and workplaces	34.40%	364
Hospitals	10.49%	111
Physicians	30.62%	324
Pharmacists	4.16%	44
Aging services and senior centers	41.30%	437

Churches and faith communities	27.32%	289
Veterans Administration	5.77%	61
Public Service Announcements on radio or television	43.29%	458
Website	9.92%	105
Social media	48.11%	509
First responders	4.25%	45
Libraries	3.31%	35
Alzheimer's Association	24.48%	259
State Agency	4.25%	45
Print (magazines, newspapers, etc.)	18.05%	191
Other (please specify)	4.35%	46
Total Respondents: 1,058		

## Q7 Have you ever seen any dementia related material in the following forms in Kansas? (check all that apply)

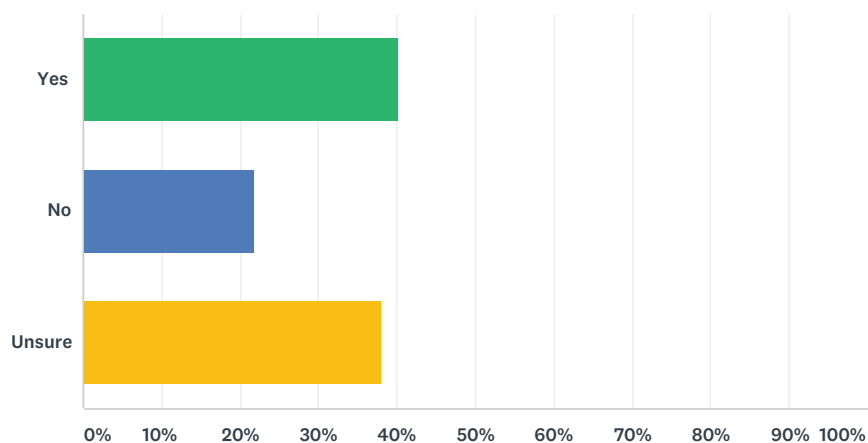
Answered: 967 Skipped: 99



ANSWER CHOICES	RESPONSES	
Social media	54.50%	527
Television	52.64%	509
Radio	15.93%	154
Print (newspaper, magazines, brochures)	79.01%	764
Total Respondents: 967		

## Q8 Would you be interested in participating in Alzheimer's Disease research?

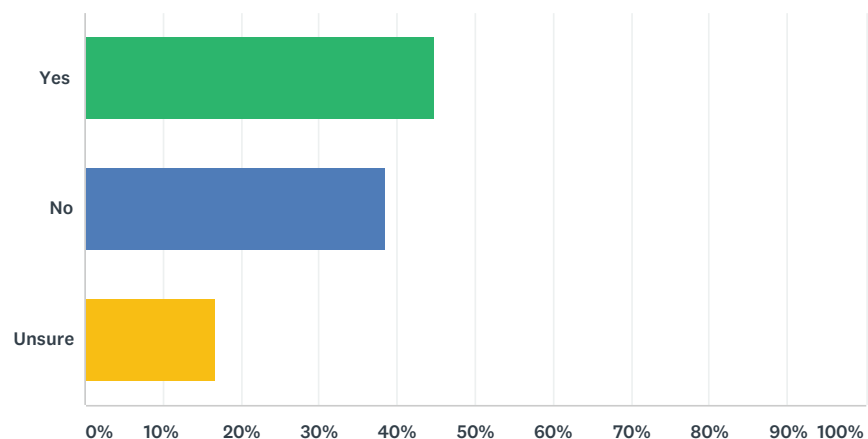
Answered: 1,057 Skipped: 9



ANSWER CHOICES	RESPONSES	
Yes	40.11%	424
No	21.85%	231
Unsure	38.03%	402
TOTAL		1,057

## Q9 Do you know where to find information on research studies in your area?

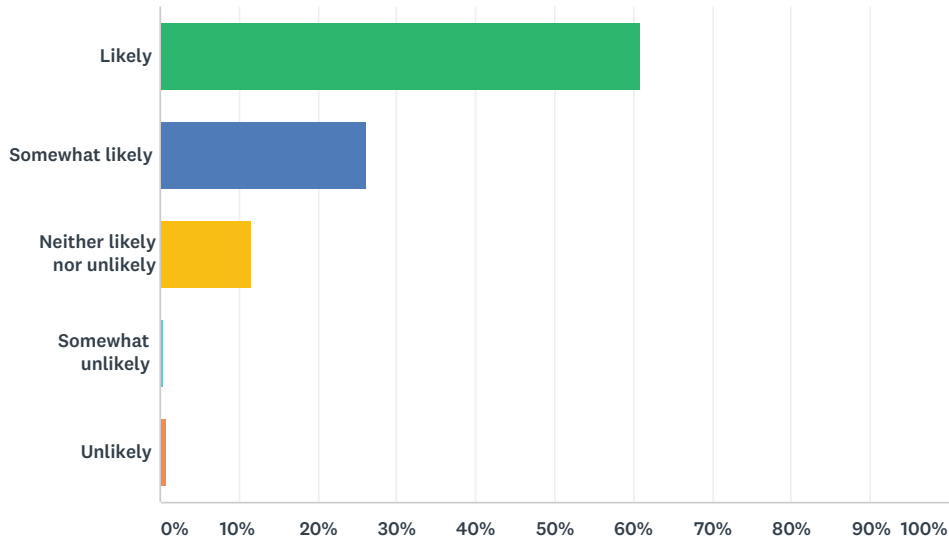
Answered: 1,059 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	44.85%	475
No	38.43%	407
Unsure	16.71%	177
TOTAL		1,059

Q10 If an elected official supports legislation that will help those with Alzheimer's disease and their caregivers, how much more likely would you support that elected official?

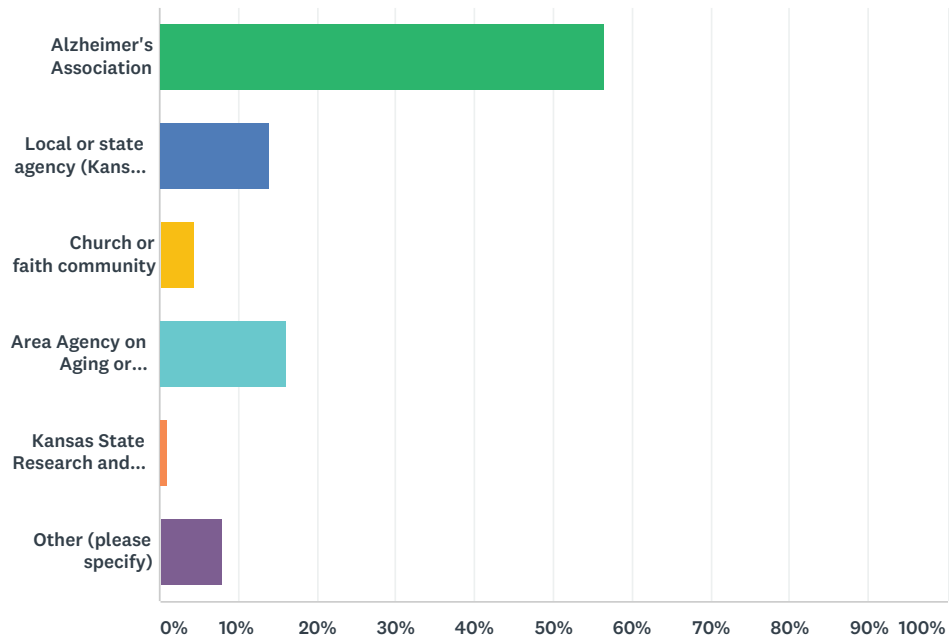
Answered: 1,057 Skipped: 9



ANSWER CHOICES	RESPONSES	
Likely	60.93%	644
Somewhat likely	26.21%	277
Neither likely nor unlikely	11.54%	122
Somewhat unlikely	0.47%	5
Unlikely	0.85%	9
TOTAL		1,057

## Q11 If an immediate family member was diagnosed with Alzheimer's or other dementias, what outside source would you first contact for help?

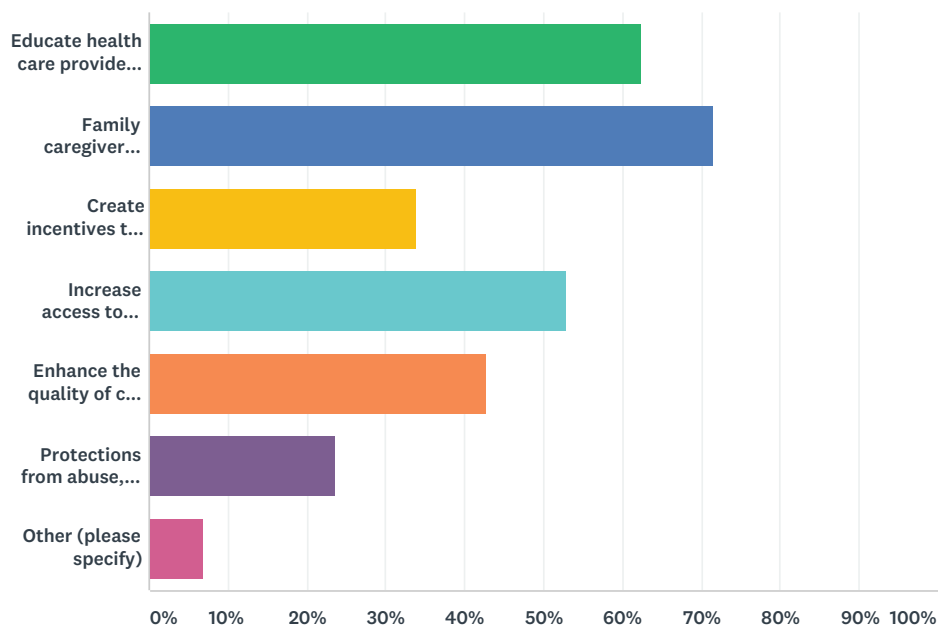
Answered: 1,058 Skipped: 8



ANSWER CHOICES	RESPONSES	
Alzheimer's Association	56.43%	597
Local or state agency (Kansas Dept. of Aging and Disability or Kansas Dept. of Health and Environment or other government agency)	13.99%	148
Church or faith community	4.35%	46
Area Agency on Aging or similar organization	16.16%	171
Kansas State Research and Extension Office	1.13%	12
Other (please specify)	7.94%	84
TOTAL		1,058

## Q12 In your opinion what are the three most critical issues that Kansas should address in the next five years? (Choose up to three)

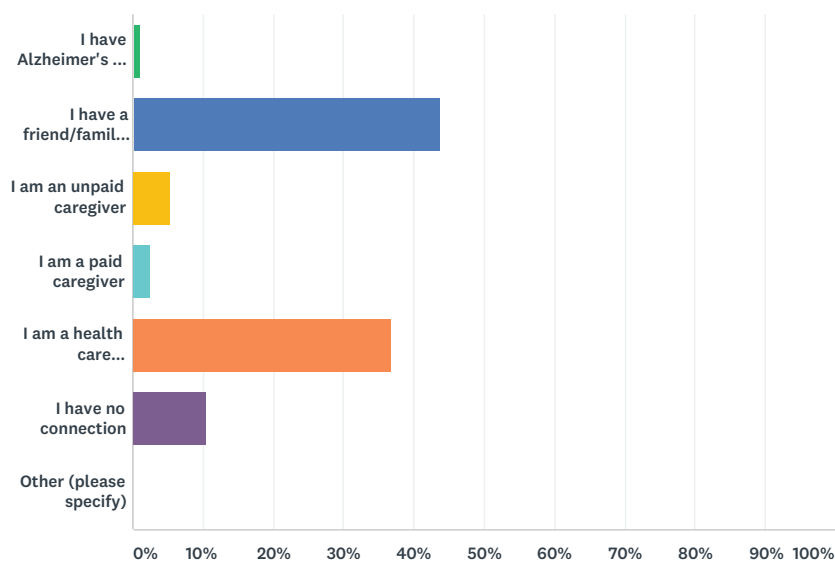
Answered: 1,062 Skipped: 4



ANSWER CHOICES	RESPONSES	
Educate health care providers and the public about early detection and diagnosis	62.34%	662
Family caregiver education and support	71.56%	760
Create incentives to recruit and retain health care professionals	33.80%	359
Increase access to respite and adult day care	52.92%	562
Enhance the quality of care in nursing homes	42.75%	454
Protections from abuse, neglect and exploitation	23.73%	252
Other (please specify)	6.97%	74
Total Respondents: 1,062		

## Q13 What is your connection to Alzheimer's disease or other dementias?

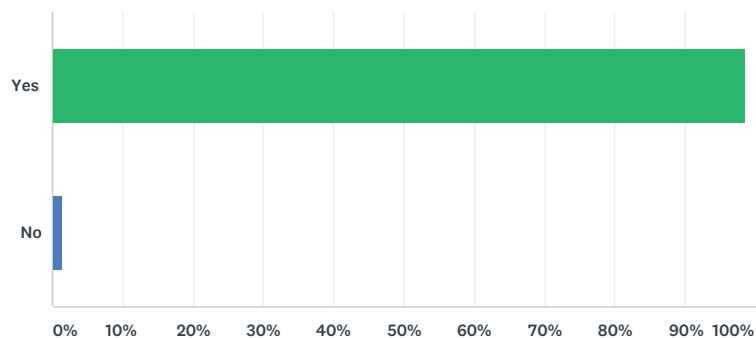
Answered: 1,061 Skipped: 5



ANSWER CHOICES	RESPONSES	
I have Alzheimer's or other dementia	0.94%	10
I have a friend/family with Alzheimer's	43.83%	465
I am an unpaid caregiver	5.47%	58
I am a paid caregiver	2.45%	26
I am a health care professional	36.76%	390
I have no connection	10.56%	112
Other (please specify)	0.00%	0
TOTAL		1,061

## Q14 Did you know that Alzheimer's is a type of dementia?

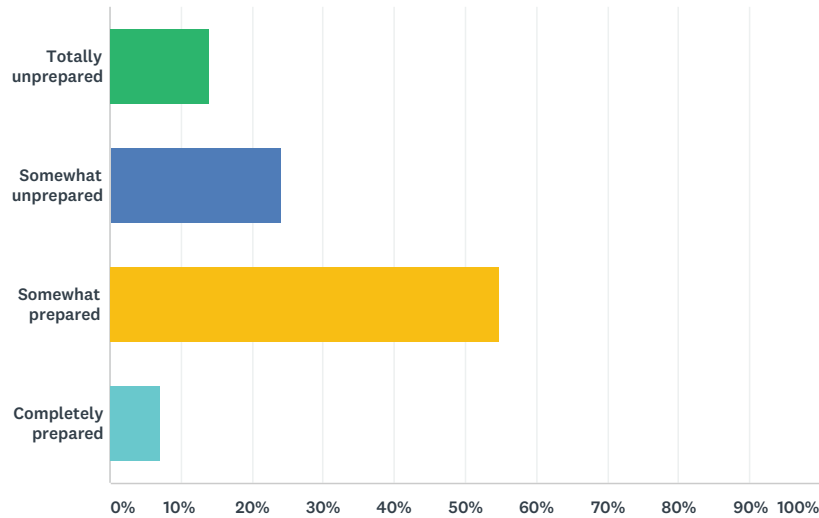
Answered: 427 Skipped: 639



ANSWER CHOICES	RESPONSES	
Yes	98.59%	421
No	1.41%	6
TOTAL		427

## Q15 How prepared do you feel you are to meet the care needs of the family member who develops Alzheimer's disease?

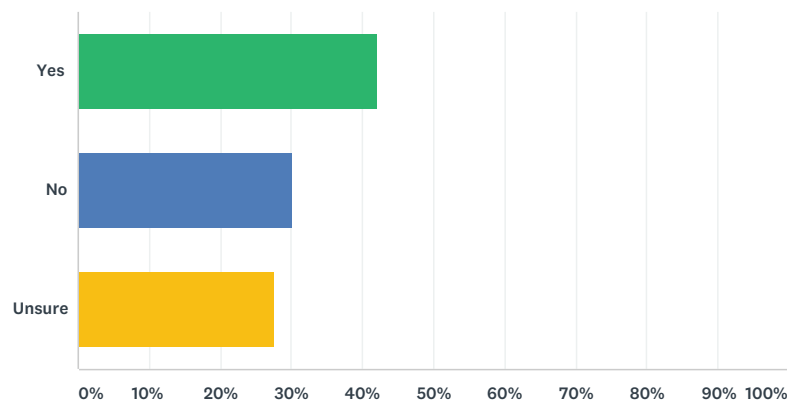
Answered: 428 Skipped: 638



ANSWER CHOICES	RESPONSES	
Totally unprepared	14.02%	60
Somewhat unprepared	24.07%	103
Somewhat prepared	54.91%	235
Completely prepared	7.01%	30
TOTAL		428

## Q16 Are you comfortable providing care to someone with dementia at home?

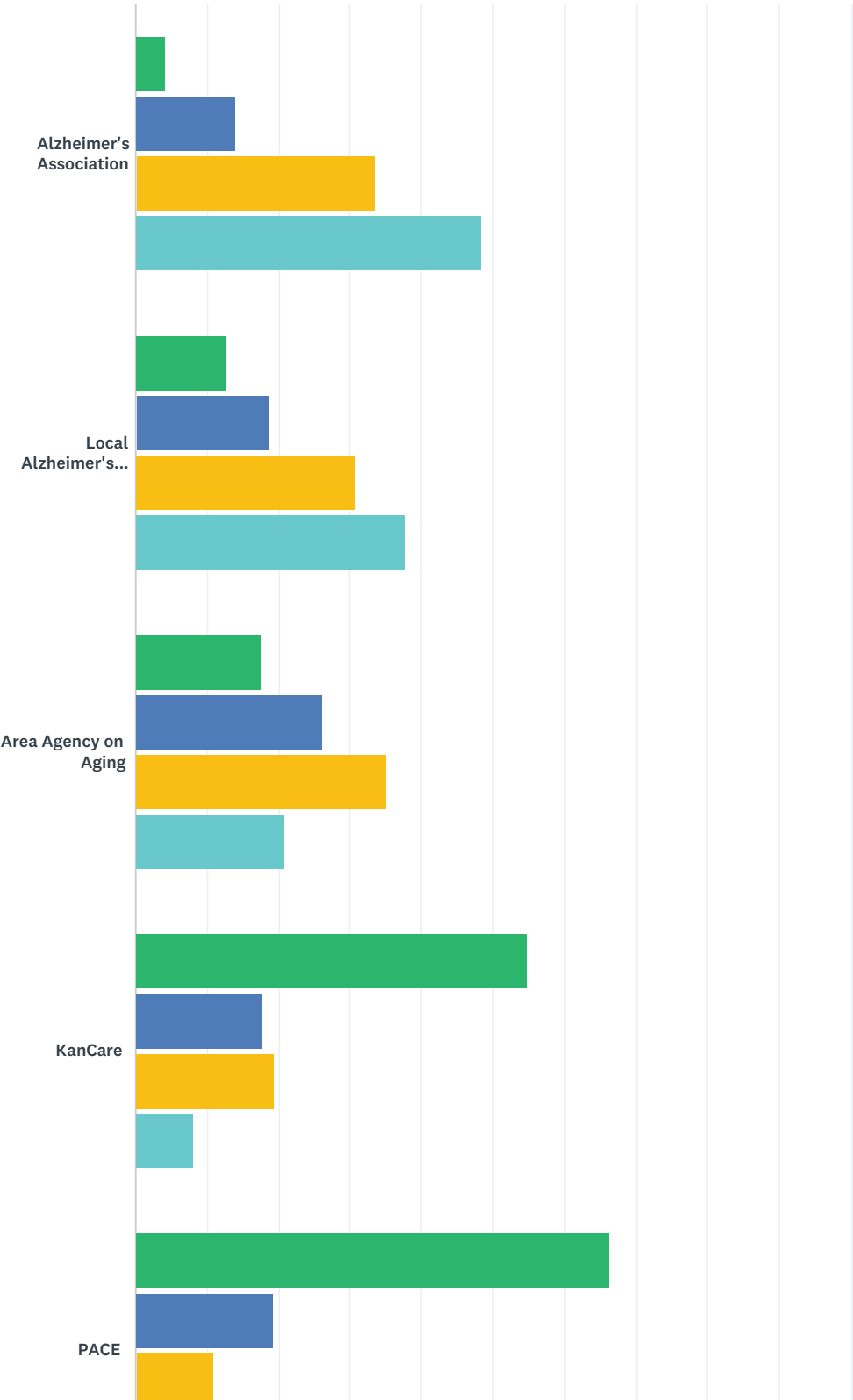
Answered: 427 Skipped: 639

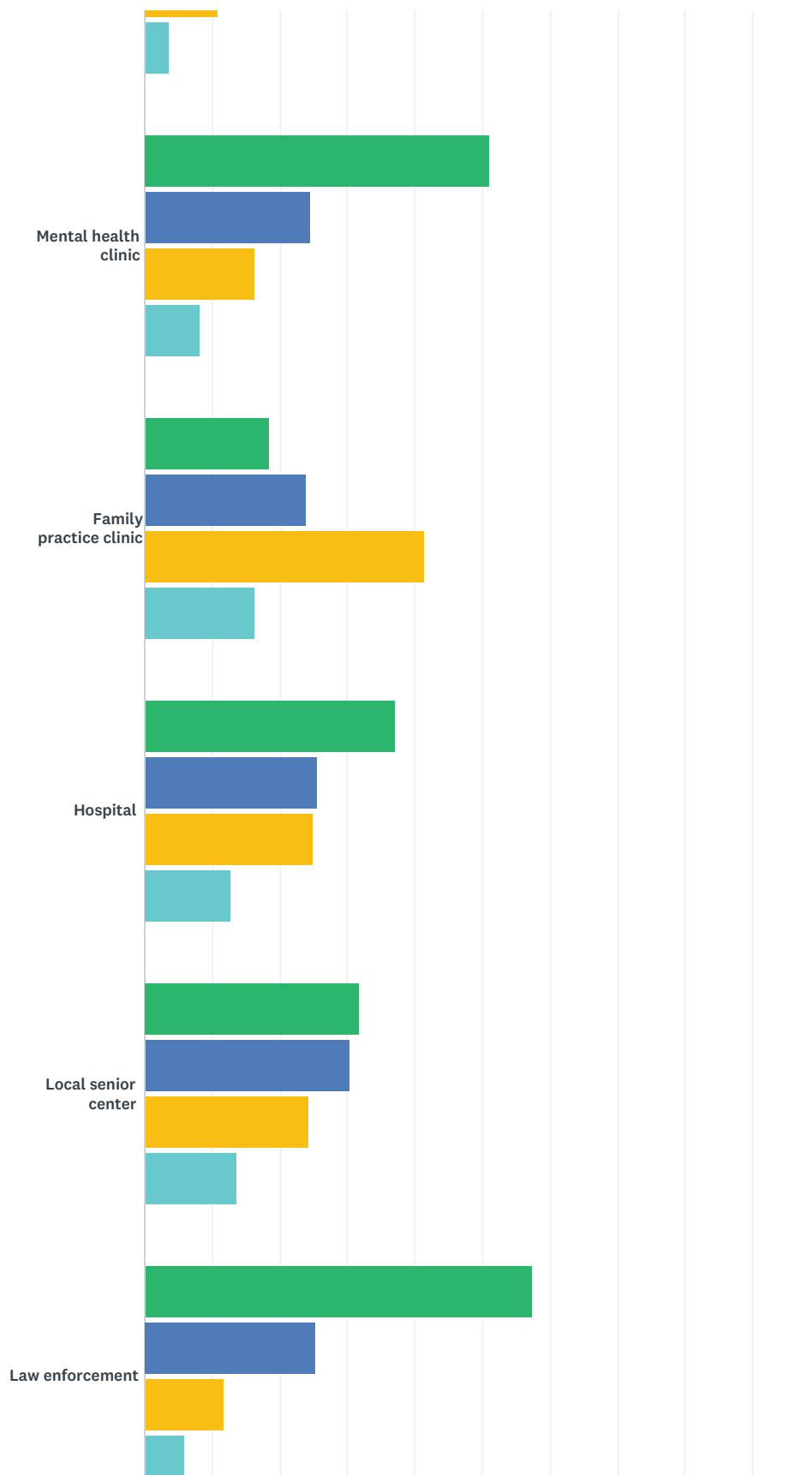


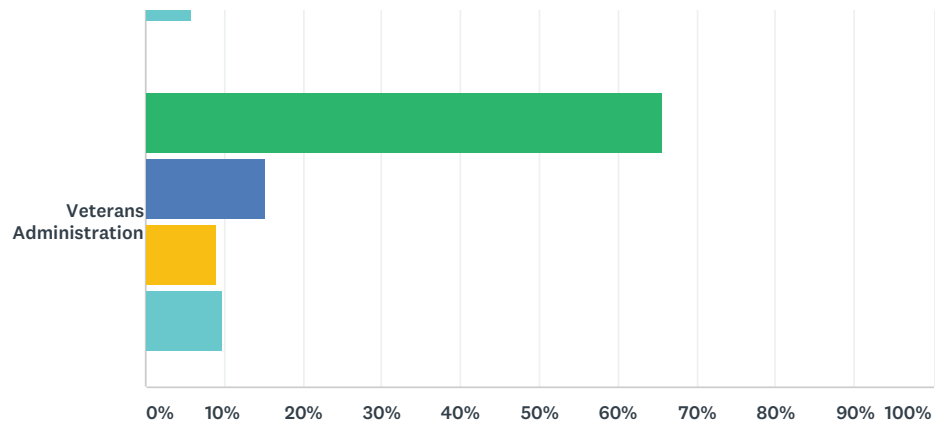
ANSWER CHOICES	RESPONSES	
Yes	42.15%	180
No	30.21%	129
Unsure	27.63%	118
TOTAL		427

Q18 What agencies have you contacted for care or guidance help?

Answered: 367    Skipped: 699





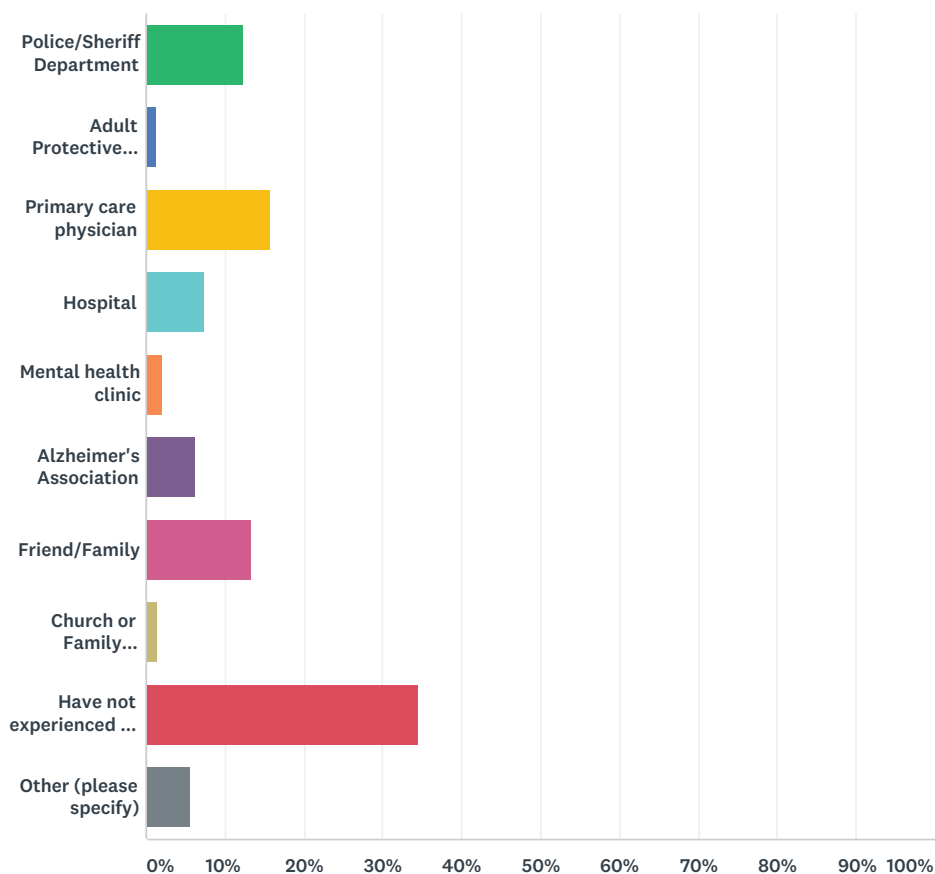


■ Not helpful
 ■ Slightly helpful
 ■ Somewhat helpful
 ■ Very helpful

	NOT HELPFUL	SLIGHTLY HELPFUL	SOMEWHAT HELPFUL	VERY HELPFUL	TOTAL	WEIGHTED AVERAGE
Alzheimer's Association	4.20% 12	13.99% 40	33.57% 96	48.25% 138	286	3.26
Local Alzheimer's support group	12.77% 24	18.62% 35	30.85% 58	37.77% 71	188	2.94
Area Agency on Aging	17.62% 37	26.19% 55	35.24% 74	20.95% 44	210	2.60
KanCare	54.84% 68	17.74% 22	19.35% 24	8.06% 10	124	1.81
PACE	66.27% 55	19.28% 16	10.84% 9	3.61% 3	83	1.52
Mental health clinic	51.02% 50	24.49% 24	16.33% 16	8.16% 8	98	1.82
Family practice clinic	18.44% 45	23.77% 58	41.39% 101	16.39% 40	244	2.56
Hospital	36.97% 61	25.45% 42	24.85% 41	12.73% 21	165	2.13
Local senior center	31.82% 42	30.30% 40	24.24% 32	13.64% 18	132	2.20
Law enforcement	57.28% 59	25.24% 26	11.65% 12	5.83% 6	103	1.66
Veterans Administration	65.77% 73	15.32% 17	9.01% 10	9.91% 11	111	1.63

## Q19 If a crisis was experienced, who did you contact to provide these services?

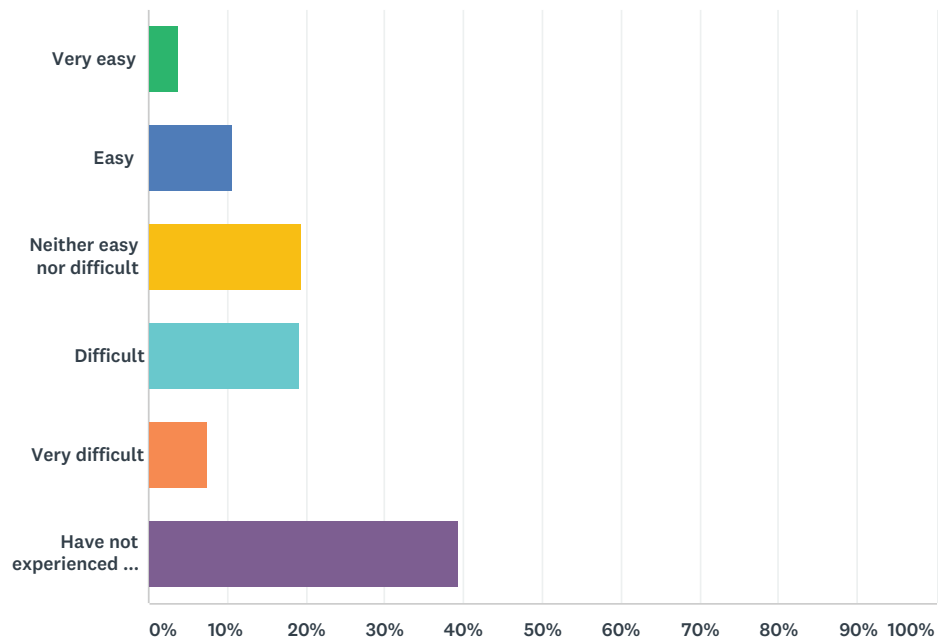
Answered: 395 Skipped: 671



ANSWER CHOICES	RESPONSES	
Police/Sheriff Department	12.41%	49
Adult Protective Services	1.27%	5
Primary care physician	15.70%	62
Hospital	7.34%	29
Mental health clinic	2.03%	8
Alzheimer's Association	6.33%	25
Friend/Family	13.42%	53
Church or Family Community	1.52%	6
Have not experienced a crisis	34.43%	136
Other (please specify)	5.57%	22
<b>TOTAL</b>		<b>395</b>

## Q20 If you've experienced a crisis with a person who has dementia, how easy was it to access necessary services?

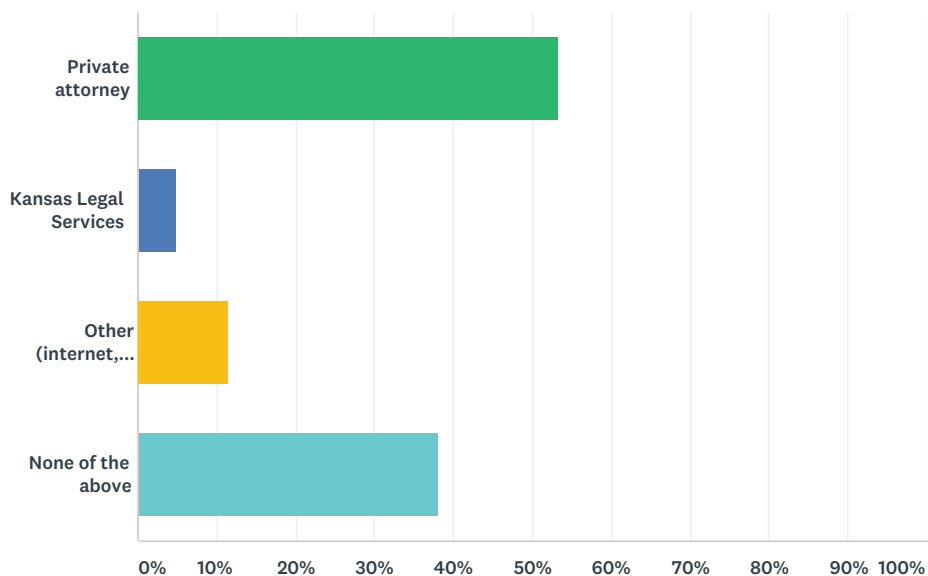
Answered: 396 Skipped: 670



ANSWER CHOICES	RESPONSES	
Very easy	3.79%	15
Easy	10.61%	42
Neither easy nor difficult	19.44%	77
Difficult	19.19%	76
Very difficult	7.58%	30
Have not experienced a crisis	39.39%	156
TOTAL		396

## Q21 Have you used to the following legal services? (check all that apply)

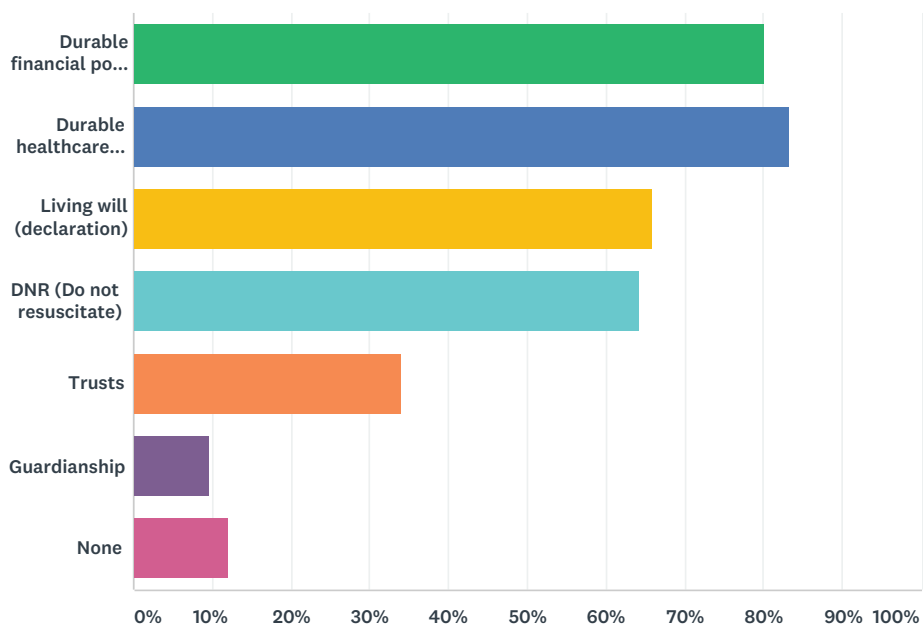
Answered: 407 Skipped: 659



ANSWER CHOICES	RESPONSES	
Private attorney	53.32%	217
Kansas Legal Services	4.91%	20
Other (internet, legal forms, etc.)	11.55%	47
None of the above	38.08%	155
Total Respondents: 407		

## Q22 Do you have the following legal documents for the person diagnosed with dementia? (check all that apply)

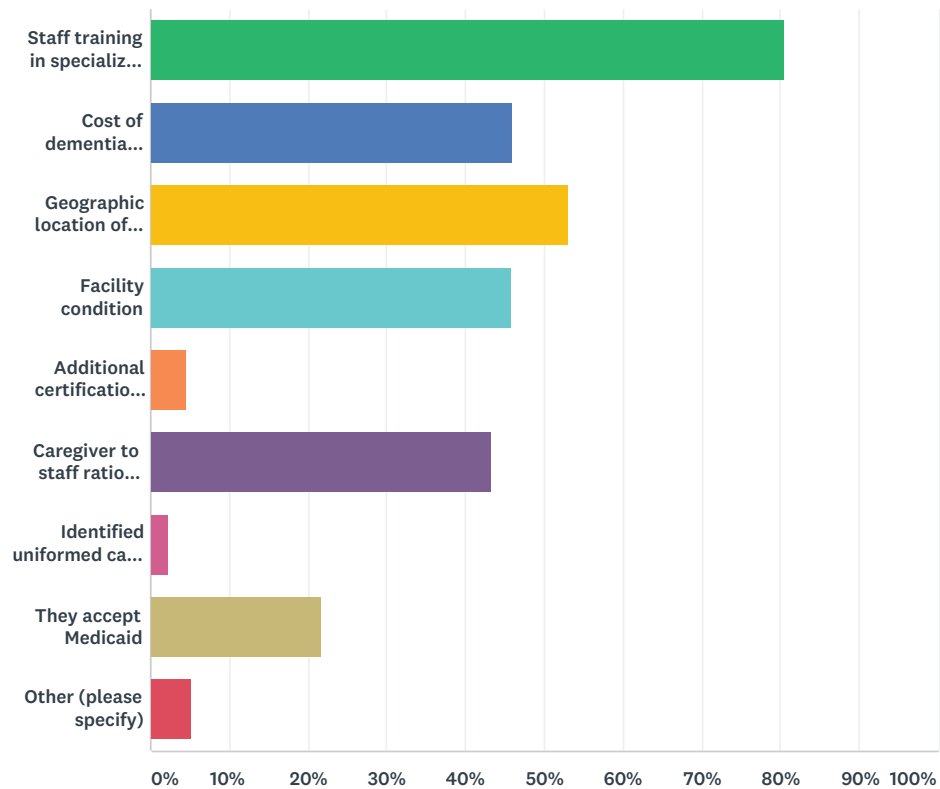
Answered: 402 Skipped: 664



ANSWER CHOICES	RESPONSES	
Durable financial power of attorney	80.10%	322
Durable healthcare power of attorney	83.33%	335
Living will (declaration)	65.92%	265
DNR (Do not resuscitate)	64.18%	258
Trusts	34.08%	137
Guardianship	9.70%	39
None	12.19%	49
Total Respondents: 402		

## Q23 When assessing care needs for a loved one that may need facility placement, which three are most important to you? (Select only three)

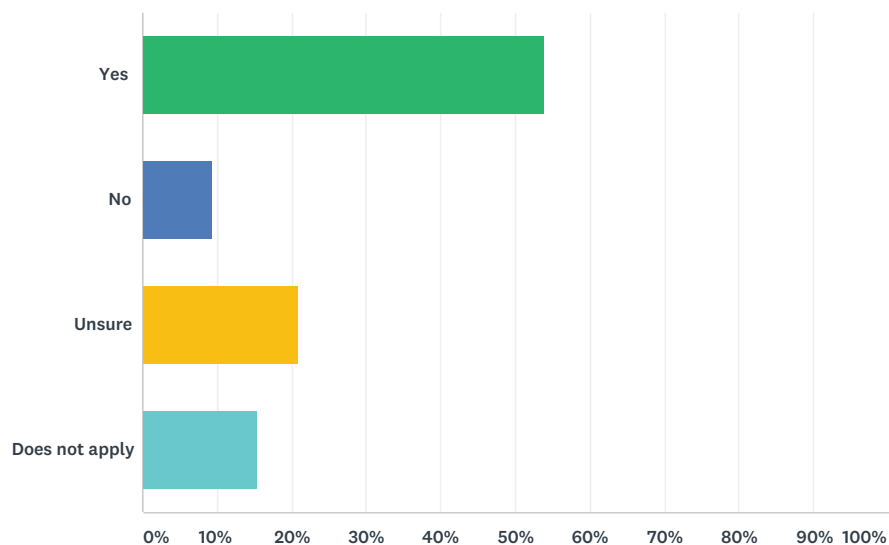
Answered: 417 Skipped: 649



ANSWER CHOICES	RESPONSES	
Staff training in specialized dementia care	80.58%	336
Cost of dementia care/memory care	46.04%	192
Geographic location of facility (is it close to primary family)	53.24%	222
Facility condition	45.80%	191
Additional certifications or designations for the facility	4.56%	19
Caregiver to staff ratio (number of caregivers to staff)	43.41%	181
Identified uniformed care standards across providers	2.40%	10
They accept Medicaid	21.82%	91
Other (please specify)	5.28%	22
Total Respondents: 417		

## Q24 Do you feel you or your loved one's Primary Care Physician continues to be supportive after an initial diagnosis of Alzheimer's or other dementia?

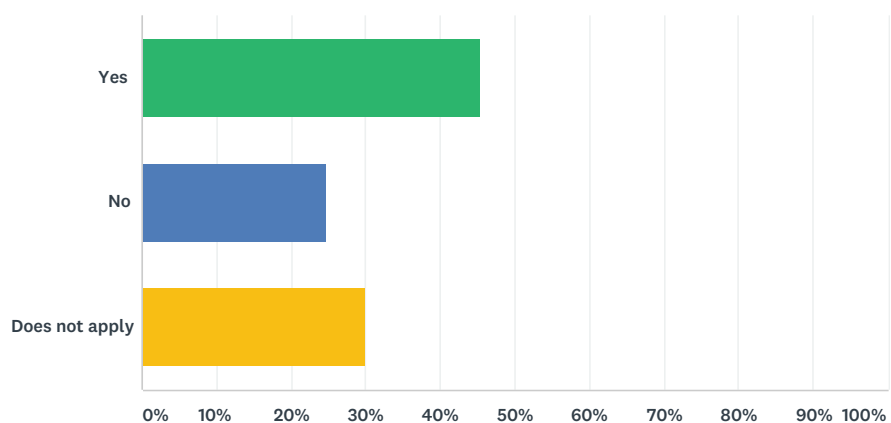
Answered: 411 Skipped: 655



ANSWER CHOICES	RESPONSES	
Yes	54.01%	222
No	9.49%	39
Unsure	20.92%	86
Does not apply	15.58%	64

## Q25 Are you currently employed while caregiving?

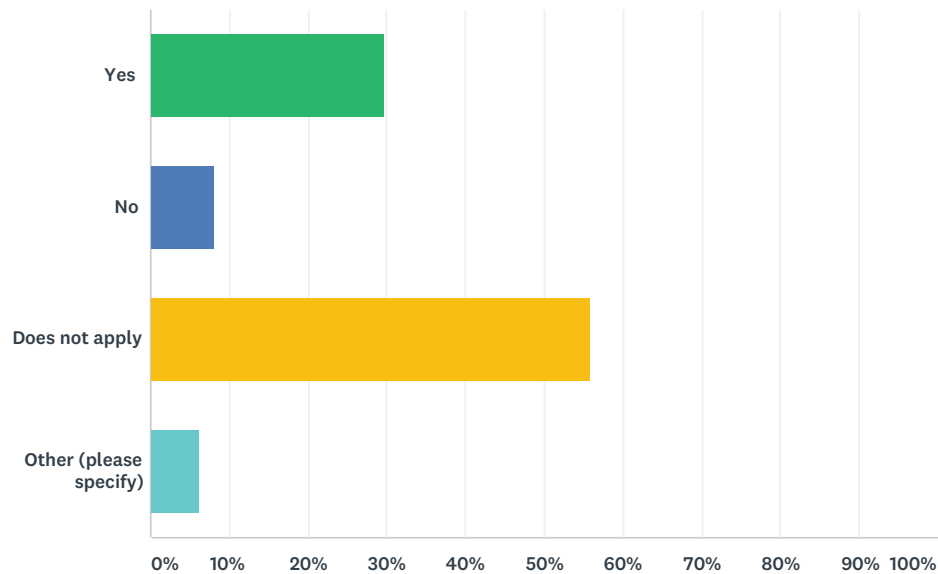
Answered: 414 Skipped: 652



ANSWER CHOICES	RESPONSES	
Yes	45.41%	188
No	24.64%	102
Does not apply	29.95%	124
TOTAL		414

## Q26 Does your employer support your special caregiver needs?

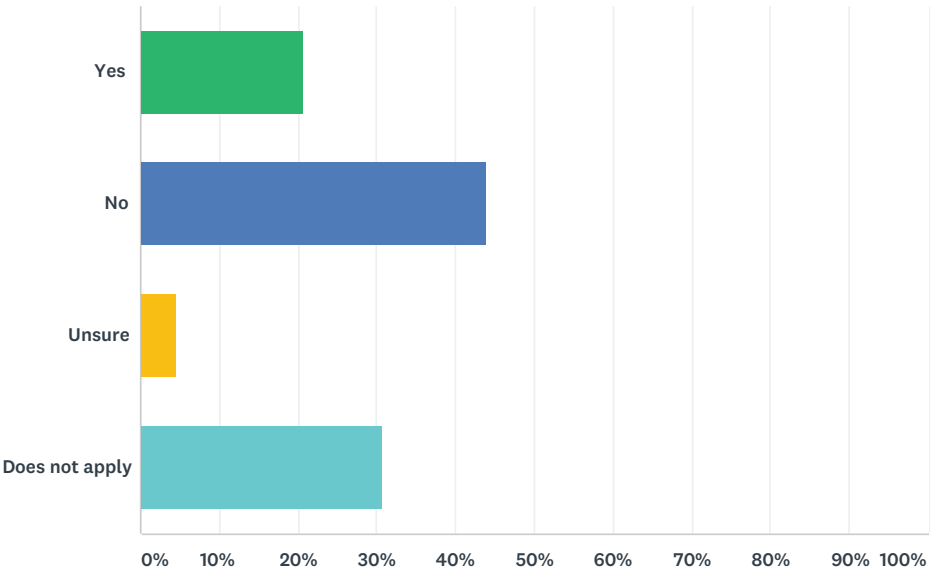
Answered: 412 Skipped: 654



ANSWER CHOICES	RESPONSES	
Yes	29.61%	122
No	8.25%	34
Does not apply	55.83%	230
Other (please specify)	6.31%	26
TOTAL		412

# Q27 Do you receive any regular training or updates on caring for someone with Alzheimer's or other dementia at home?

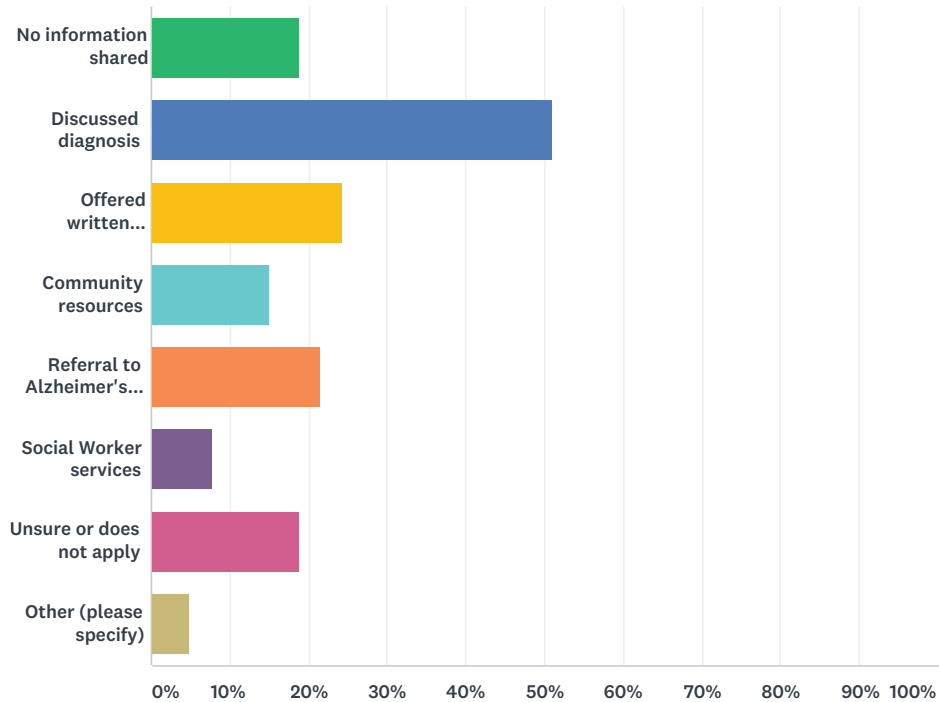
Answered: 415 Skipped: 651



ANSWER CHOICES	RESPONSES	
Yes	20.72%	86
No	43.86%	182
Unsure	4.58%	19
Does not apply	30.84%	128
TOTAL		415

**Q28 When you or your friend/family member were given a diagnosis of Alzheimer's or other dementia, what kind of information did the provider or medical staff offer about the illness itself, planning for care, community resources or referrals? (Choose all that apply)**

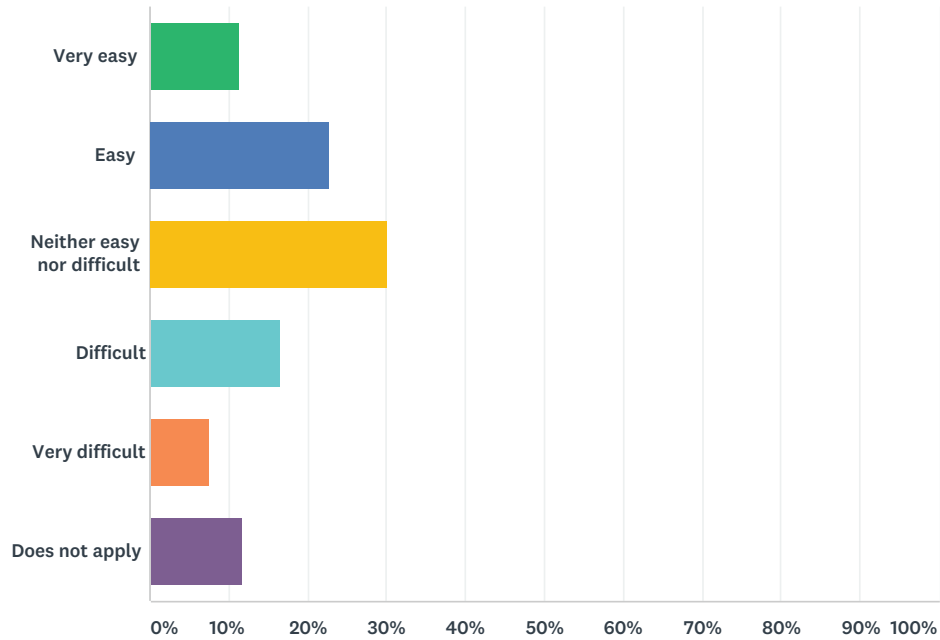
Answered: 413 Skipped: 653



ANSWER CHOICES	RESPONSES	
No information shared	18.89%	78
Discussed diagnosis	51.09%	211
Offered written information	24.21%	100
Community resources	15.01%	62
Referral to Alzheimer's Association	21.55%	89
Social Worker services	7.75%	32
Unsure or does not apply	18.89%	78
Other (please specify)	4.84%	20
Total Respondents: 413		

## Q29 How difficult was it for you (or your friend/family member with Alzheimer's dementia) to get a medical assessment/diagnosis from a local physician?

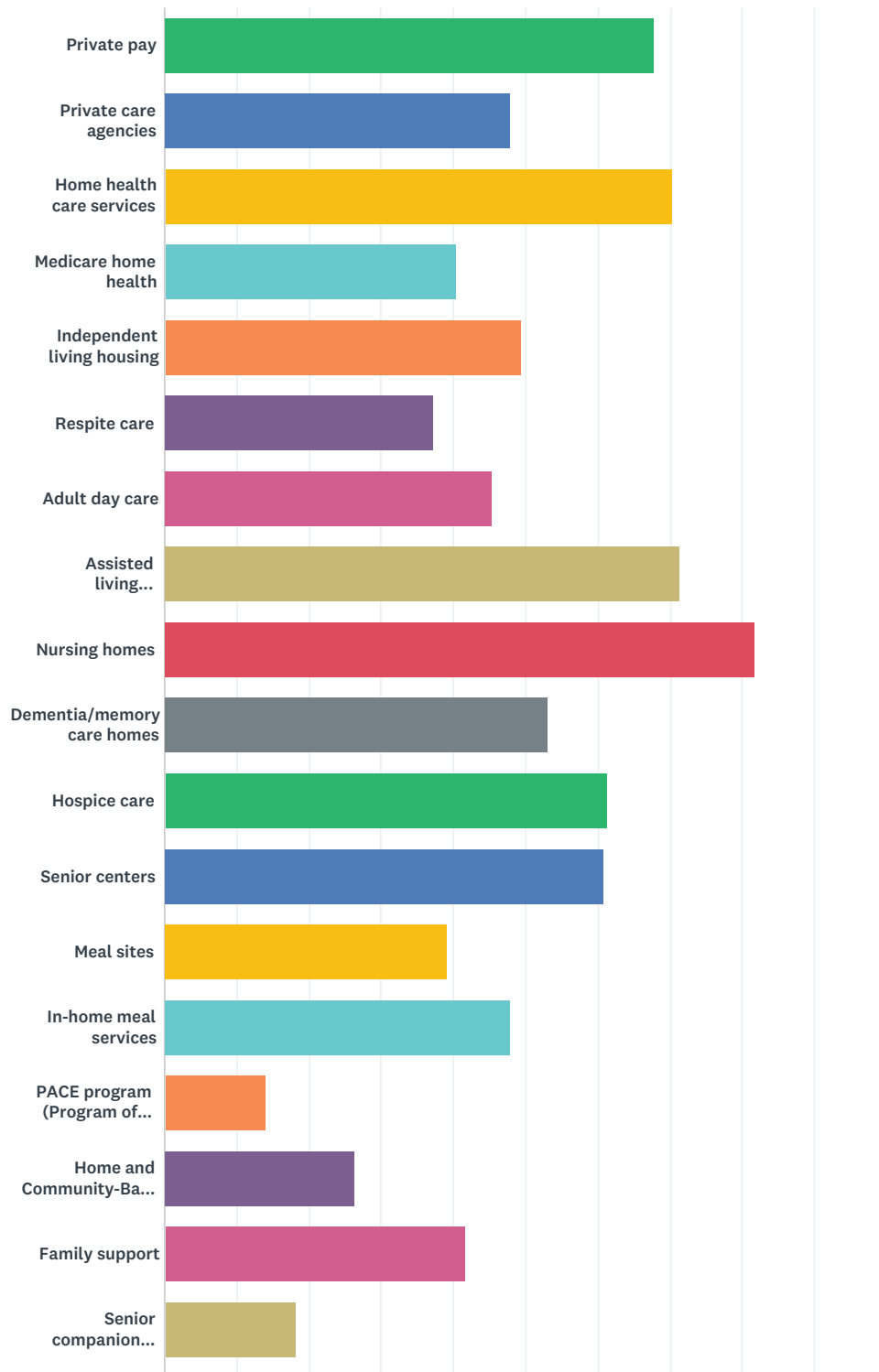
Answered: 409 Skipped: 657

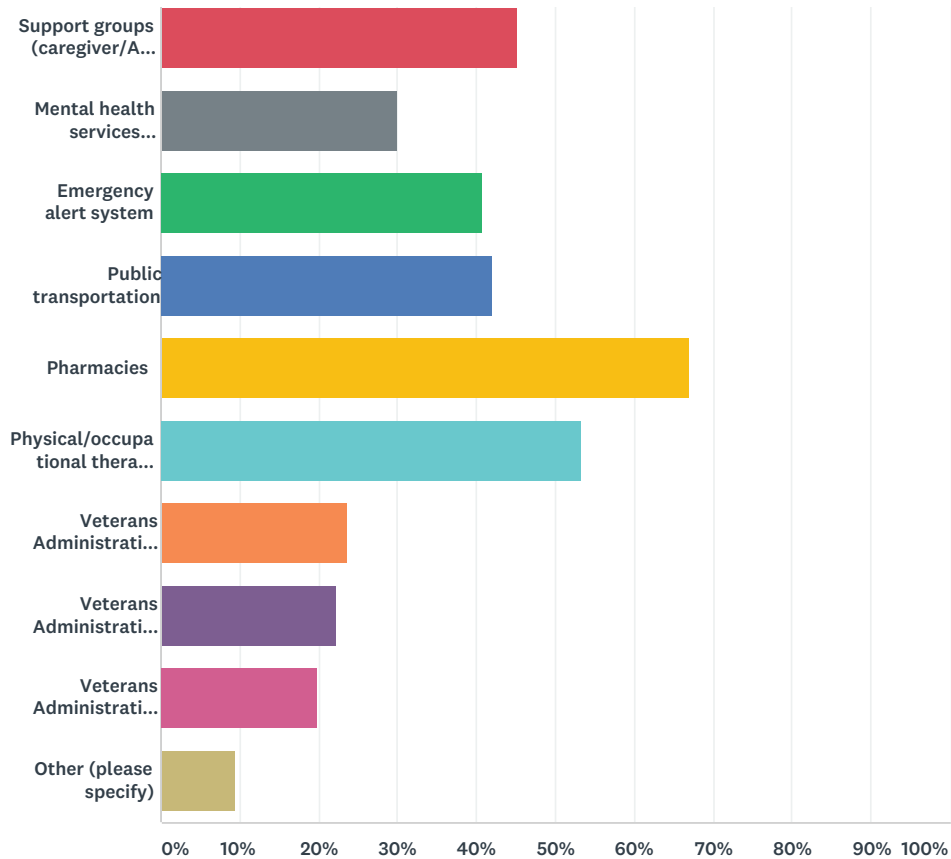


ANSWER CHOICES	RESPONSES	
Very easy	11.25%	46
Easy	22.74%	93
Neither easy nor difficult	30.07%	123
Difficult	16.63%	68
Very difficult	7.58%	31
Does not apply	11.74%	48
TOTAL		409

## Q30 What care resources are available to you in your county? (Choose all that apply)

Answered: 397 Skipped: 669





ANSWER CHOICES	RESPONSES	
Private pay	67.76%	269
Private care agencies	47.86%	190
Home health care services	70.28%	279
Medicare home health	40.30%	160
Independent living housing	49.37%	196
Respite care	37.28%	148
Adult day care	45.34%	180
Assisted living facilities	71.28%	283
Nursing homes	81.86%	325
Dementia/memory care homes	53.15%	211
Hospice care	61.21%	243
Senior centers	60.96%	242
Meal sites	39.04%	155
In-home meal services	47.86%	190
PACE program (Program of All-Inclusive Care for the Elderly)	14.11%	56

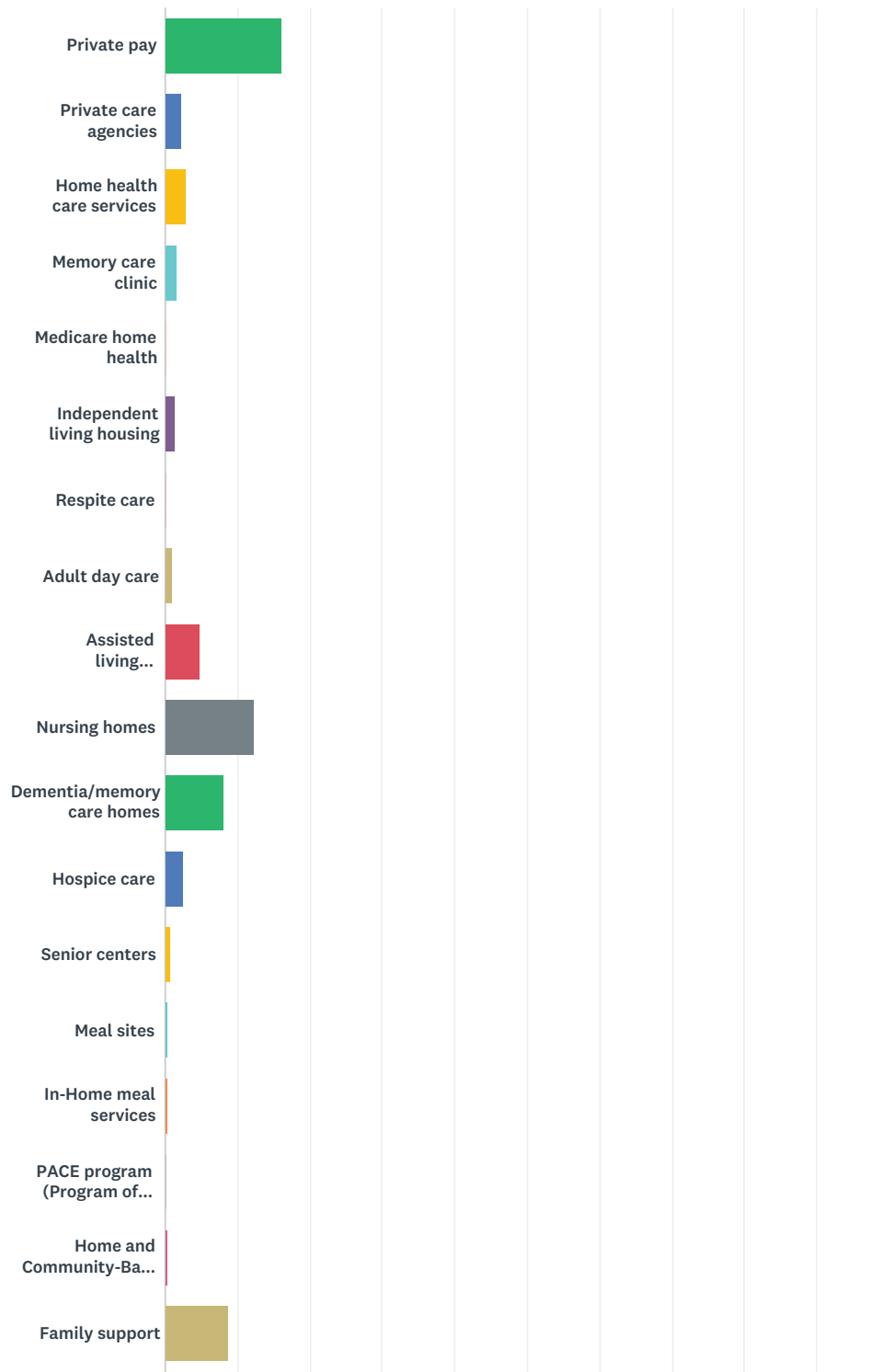
## 2019 Alzheimer's Disease Task Force Survey

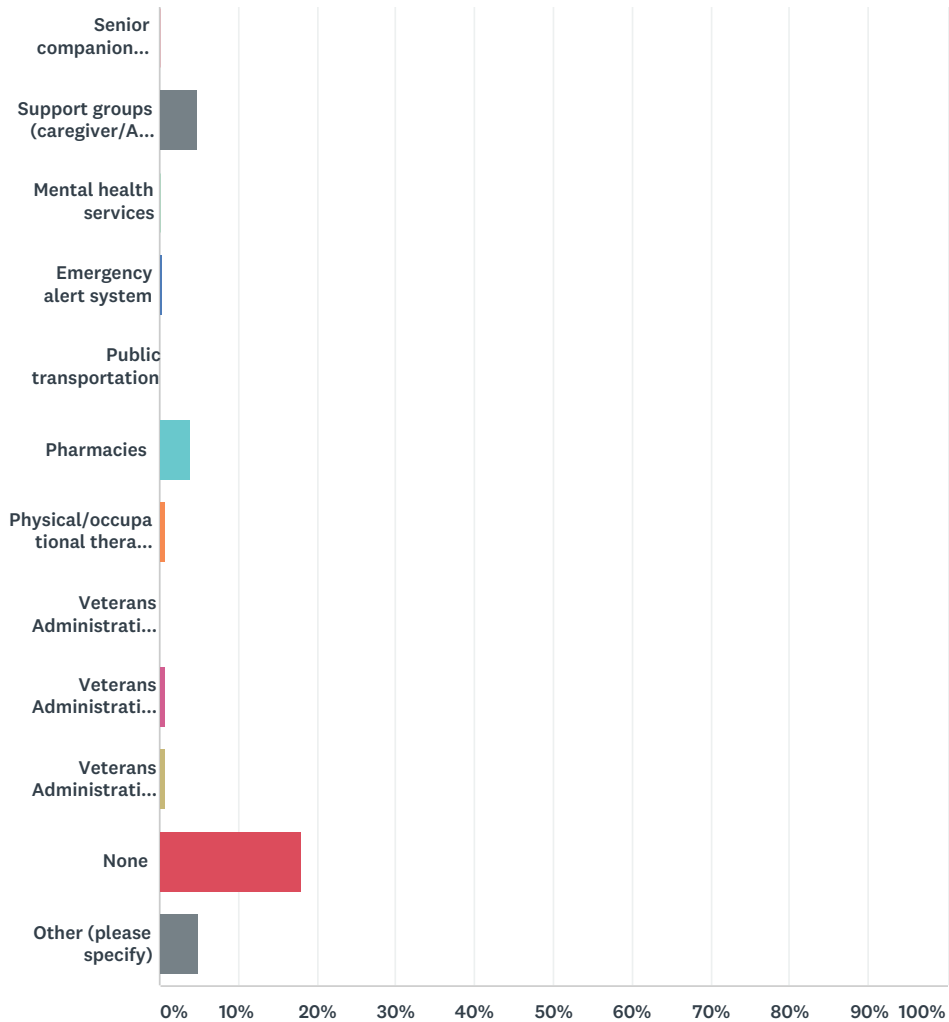
SurveyMonkey

Home and Community-Based Services (HCBS) providers	26.45%	105
Family support	41.56%	165
Senior companion program	18.14%	72
Support groups (caregiver/Alzheimer's)	45.09%	179
Mental health services (includes geriatric psychiatric services)	29.97%	119
Emergency alert system	40.81%	162
Public transportation	42.07%	167
Pharmacies	67.00%	266
Physical/occupational therapy services	53.40%	212
Veterans Administration office	23.68%	94
Veterans Administration health services	22.17%	88
Veterans Administration clinic	19.90%	79
Other (please specify)	9.32%	37
Total Respondents: 397		

# Q31 What services related to Alzheimer's or other dementia care have you used or are currently using?

Answered: 402 Skipped: 664



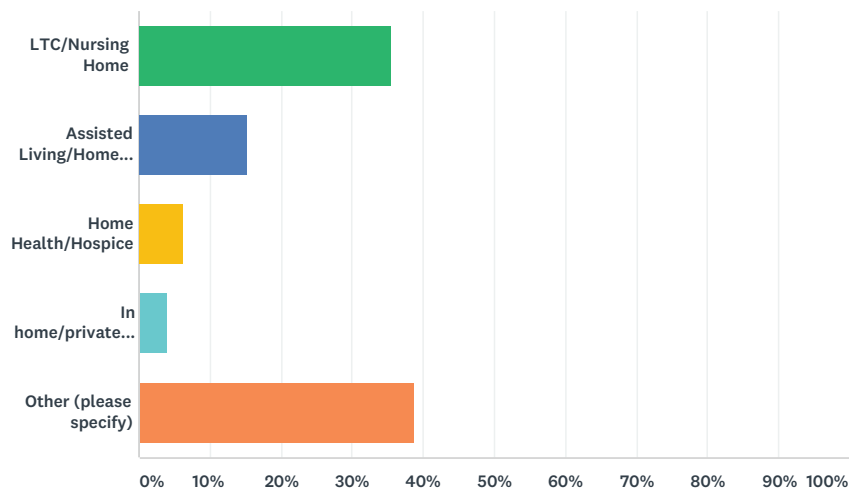


ANSWER CHOICES	RESPONSES	
Private pay	16.17%	65
Private care agencies	2.24%	9
Home health care services	2.99%	12
Memory care clinic	1.74%	7
Medicare home health	0.25%	1
Independent living housing	1.49%	6
Respite care	0.25%	1
Adult day care	1.00%	4
Assisted living facilities	4.73%	19
Nursing homes	12.44%	50
Dementia/memory care homes	8.21%	33
Hospice care	2.49%	10

Senior centers	0.75%	3
Meal sites	0.50%	2
In-Home meal services	0.50%	2
PACE program (Program of All-Inclusive Care for the Elderly)	0.25%	1
Home and Community-Based Services (HCBS) providers	0.50%	2
Family support	8.71%	35
Senior companion program	0.25%	1
Support groups (caregiver/Alzheimer's)	4.73%	19
Mental health services	0.25%	1
Emergency alert system	0.50%	2
Public transportation	0.00%	0
Pharmacies	3.98%	16
Physical/occupational therapy services	0.75%	3
Veterans Administration office	0.00%	0
Veterans Administration health services	0.75%	3
Veterans Administration clinic	0.75%	3
None	17.91%	72
Other (please specify)	4.98%	20
<b>TOTAL</b>		<b>402</b>

### Q32 What type of Community Care Provider are you?

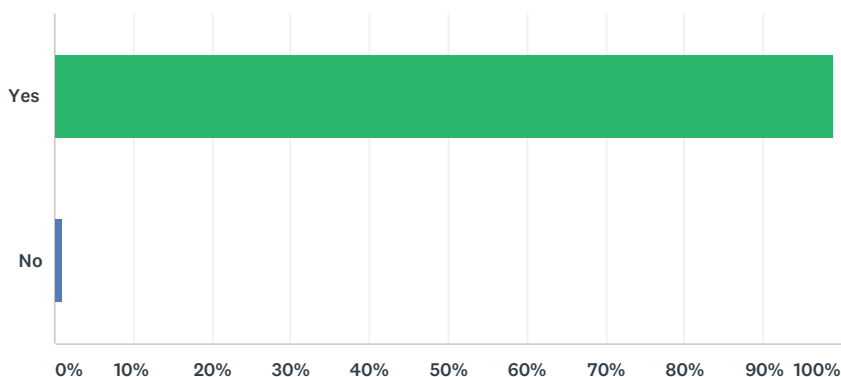
Answered: 519 Skipped: 547



ANSWER CHOICES	RESPONSES	
LTC/Nursing Home	35.65%	185
Assisted Living/Home Plus	15.22%	79
Home Health/Hospice	6.36%	33
In home/private duty care	4.05%	21
Other (please specify)	38.73%	201
<b>TOTAL</b>		<b>519</b>

### Q33 Did you know that Alzheimer's is a type of dementia?

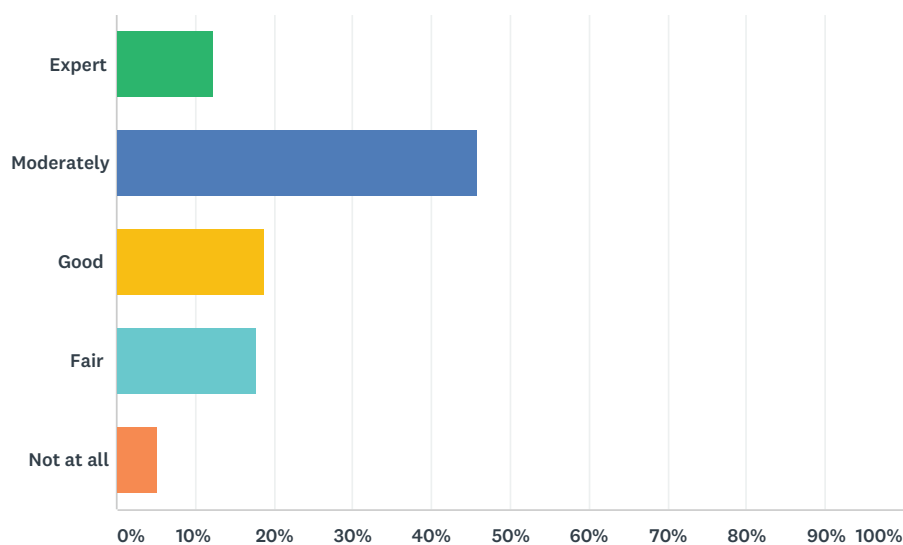
Answered: 586 Skipped: 480



ANSWER CHOICES	RESPONSES	
Yes	98.98%	580
No	1.02%	6
TOTAL		586

### Q34 How knowledgeable are you with the various types of dementia?

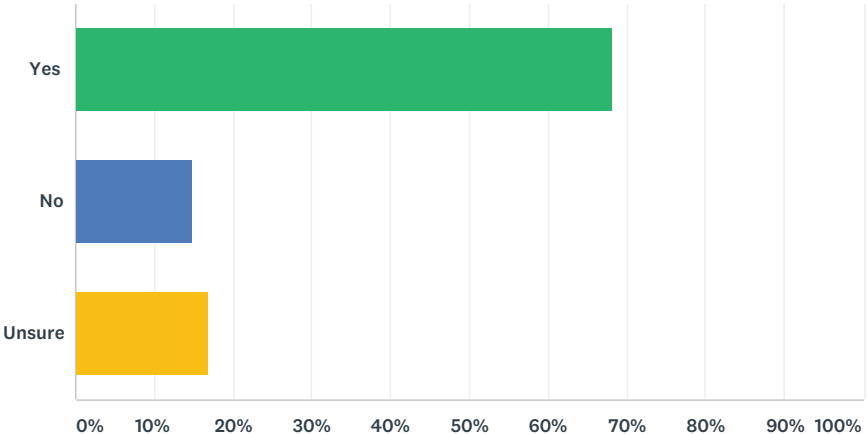
Answered: 578 Skipped: 488



ANSWER CHOICES	RESPONSES	
Expert	12.28%	71
Moderately	45.85%	265
Good	18.86%	109
Fair	17.82%	103
Not at all	5.19%	30
TOTAL		578

Q36 Do you feel comfortable providing dementia care in your community/practice?

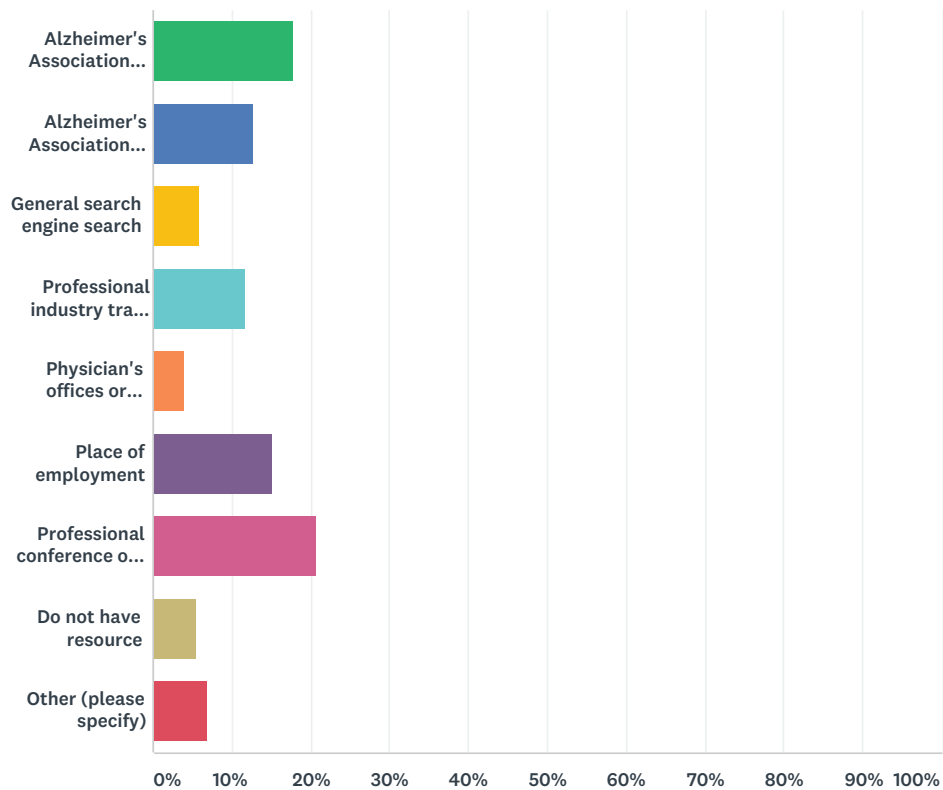
Answered: 548 Skipped: 518



ANSWER CHOICES	RESPONSES	
Yes	68.25%	374
No	14.78%	81
Unsure	16.97%	93
TOTAL		548

## Q37 Where do you get information on dementia for your facility/practice?

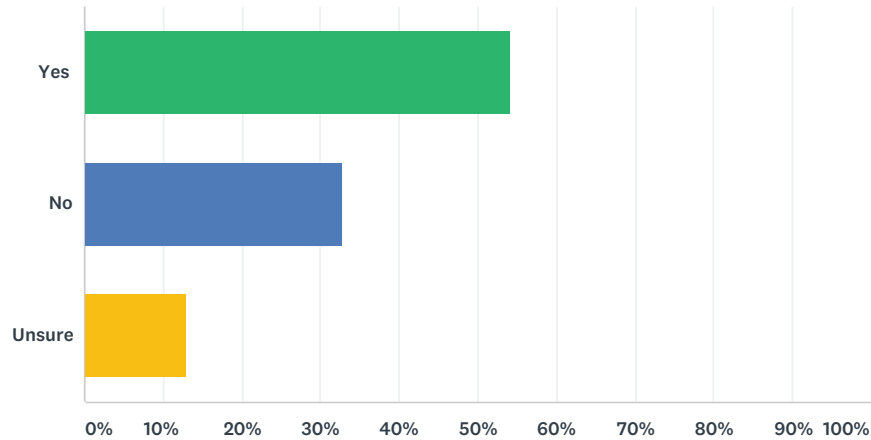
Answered: 537 Skipped: 529



ANSWER CHOICES	RESPONSES	
Alzheimer's Association website	17.69%	95
Alzheimer's Association training and staff	12.85%	69
General search engine search	5.77%	31
Professional industry trade resources	11.73%	63
Physician's offices or contacts	3.91%	21
Place of employment	15.08%	81
Professional conference or training	20.67%	111
Do not have resource	5.40%	29
Other (please specify)	6.89%	37
TOTAL		537

## Q39 Does your organization require dementia training?

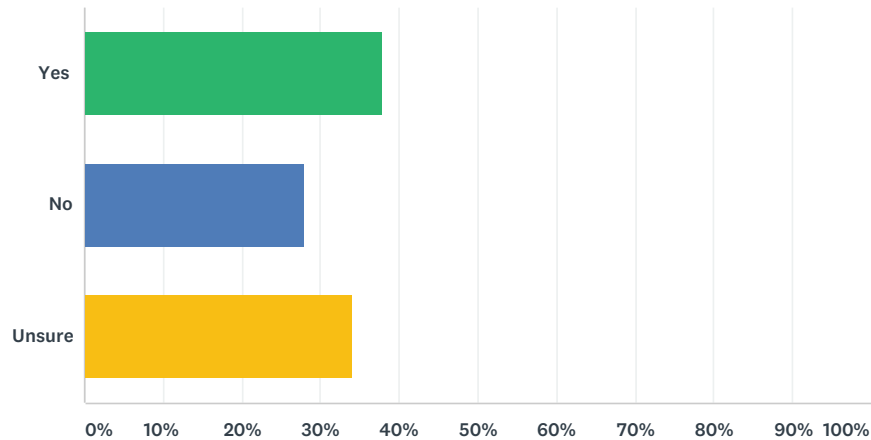
Answered: 523 Skipped: 543



ANSWER CHOICES		RESPONSES	
Yes		54.11%	283
No		32.89%	172
Unsure		13.00%	68
TOTAL			523

## Q40 If your organization offers training, do you consider it adequate?

Answered: 499 Skipped: 567



ANSWER CHOICES		RESPONSES	
Yes		37.88%	189
No		28.06%	140
Unsure		34.07%	170
TOTAL			499