

# The Impact of Alzheimer's on Arkansas Families



#### Prevalence

NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S

Year TOTAL

2020 **58,000** 

2025 67,000

**ESTIMATED % CHANGE** 

15.5%

#### Health Care

HOSPICE (2017)

3,133

# of people in hospice with a primary diagnosis of dementia

18%

% in hospice with a primary diagnosis of dementia

HOSPITALS (2018)

1,530

# of emergency department visits per 1,000 people with dementia

21.5%

dementia patient hospital readmission rate

MEDICAID

\$396M

Medicaid costs of caring for people with Alzheimer's (2020)

14.6%

projected change in costs from 2020 to 2025

MEDICARE

\$23,982

per capita Medicare spending on people with dementia (in 2021 dollars)

\*Source: Alzheimer's Disease Facts and Figures 2022

## What makes Alzheimer's Unique from other Chronic diseases?

- Prevention Though research is still evolving, evidence is strong that people can reduce their risk by making key lifestyle changes, including participating in regular activity and maintaining good heart health.
- Diagnosis There is no single diagnostic test that can determine if a person has Alzheimer's disease.
- Treatment There's no cure for Alzheimer's, but there are treatments that may change disease progression, and drug and non-drug options that may help treat symptoms.

## What makes Alzheimer's Unique from other Chronic diseases?

- Impact on Comorbid conditions BRFSS indicates many with other chronic conditions also have subjective cognitive decline.
- Age of those impacted -
  - Most are over age 65.
  - Younger Onset limits access to services.
- Lack of federal funding for states BOLD funds some programs, but it does not provide a dedicated funding source to all states like other chronic disease programs

#### Alzheimer's and Dementia State Plan

State Plan (2022-2026) General Outline

#### A. SECTION ONE

1. Introduction (Process and Exec. summary)

#### **B. SECTION TWO**

- 1. Alzheimer's and Dementia Definitions
- 2. Risk Factors, Warning Signs, etc.)

#### C. SECTION THREE (Priority Issues and recommendations)

- 1. Public Awareness
- 2. Access to Care
- 3. Family Caregiver Support
- 4. Dementia Training/Workforce Development
- D. Appendix and References



### **SECTION ONE: Introduction and Process**

#### General Outline and Section Areas

- Access and Quality of Care
- Public Awareness
- Family Caregiver Support
- Strengthening the Healthcare Workforce and ensure Dementia capable.

\*National Healthy Brain Initiative Roadmap Series -Centers of Disease Control





State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map



## History of State Government Response to Alzheimer's

- 1980s State's Begin to respond to the unique needs of individuals with Alzheimer's
- The Alzheimer's Disease and Related Disorders Advisory Committee was established within the California Health and Human Services Agency in 1988
- In 1985, Florida created the Alzheimer's Disease Initiative (ADI) within the Department of Elder Affairs (DOEA). ○ Virginia established the Alzheimer's Disease and Related Disorders Commission and the Alzheimer's and Related Diseases Research Award Fund in 1982.

#### Arkansas Response **NAPA Signed into** federal Law Establishing a National Plan to Address 2018 Silver Alert Announced 2009 Alzheimer's Disease in Arkansas 2011 ACT 92 Establishing Independent The Task Force 2012 the Task Force on the on the Effect 2009 Working Group of Alzheimer's effect of Alzheimer's Convened to Disease begin update to Alz. State Plan 201I Final Report

## Arkansas Response

February 2019 Full legislative support of the Alzheimer's and Dementia Advisory Council ACT 391 Authorizing Legislation to fund the Pilot Dementia Caregiver Respite
Grant \$200k

November 2021

January 2022 October 2022

Bipartisan support of the Alzheimer's Awareness Day Resolution

March 2021

Arkansas Awarded Federal Funding under the BOLD ACT Alzheimer's Dementia Advisory Council Approves updated Alzheimer's and Dementia State Plan

### Alzheimer's and Dementia Advisory Council

### ACT 391 of the 2021 Legislative Session

- I. Establishes an Alzheimer's and Dementia Advisory Council
- II. Requires the State Alzheimer's Disease Plan to be updated every four years
- III. Mandated Reporting to the Legislative Body on the Status of the Implementation Every Other Year



## Alzheimer's and Dementia Advisory Council



Senator Ricky Hill Co-Chair (ADAC)



Representative Julie Mayberry Co-Chair (ADAC)

## State Agency Partners

AR. Department of Health

AR. Department of Human Services

AR. Minority Health Commission

## Alzheimer's and Dementia Advisory Council

- AARP
- Alzheimer's Association
- Alzheimer's Arkansas
- Arkansas HealthCare Association
- Arkansas Hospital
   Association
- Broyles Foundation

- Homecare Association of Arkansas
- Hospice and Palliative Care Association of Arkansas
- The University of Arkansas for Medical Sciences Centers on Aging

## Establishing the Position of Dementia Services Coordinator

- A State Dementia Services Coordinator is an individual (or team of individuals) within the state government whose job is to ensure coordination of Alzheimer's programs and policies across state agencies.
- Assist with the coordination of the Alzheimer's and Dementia Advisory Council
- Establish and maintain relationships with all relevant state agencies and community organizations in order to meet community needs and prevent duplication of services
- Evaluate existing Alzheimer's and dementia programs and services Identify service gaps within the state government
- Increase awareness of and facilitate access to quality, coordinated care for people with dementia.



#### **Public Awareness**

#### **NEEDS:**

- Increased public health messaging about the importance of risk reduction, early detection and diagnosis, Ten Warning Signs.
- Improve Data Collection
- Continued coordination of the state's response to Alzheimer's and other dementia

## **Public Awareness Recommendations**

- Prioritize the state's response to Alzheimer's and other dementia by permanently reauthorizing the Alzheimer's and Dementia Advisory Committee.
  - Updated Status ACT 391 of the 2021 legislative session established a permanent Alzheimer's and Dementia Advisory Council
- Establish the position of Dementia Services Coordinator within the state government
  - Create a position and obtain specific funding to hire a full time Dementia Services Coordinator (DSC) to coordinate the services provided to persons with Alzheimer's Disease and Related Dementias, providing support to the Alzheimer's and Dementia Coordinating Council."



## **Public Awareness Recommendations**

- Increase collaboration among service providers and The UAMS Centers on Aging to expand access to educational material relating to cognitive health, caregiver education and support services, and statewide dementia resources.
- Increase collaboration with the Area Agencies on Aging, to provide dementia education to the public and available resources to better equip personnel or family caregivers about the disease and how to care for those suffering from the disease and the resources available through other stakeholders.
- GOAL: To strengthen the existing public health infrastructure to better serve the needs of Arkansans who are impacted by Alzheimer's and related dementia?



### Access and Quality of Care

#### **NEEDS:**

- Coordination of existing support services
- Monitor and assess existing and future 1915(c) waivers to ensure they are inclusive of the dementia population.
- Increased Access to Care Planning Services, Dementia education, and resources

# Access and Quality of Care Recommendations

- Expand access to dementia education, training, and support services by increasing the collaboration of service providers and the Arkansas Area Agencies on Aging.
  - Establish a dementia resource center in each Area Agency on Aging
- Research and support innovative models to finance the delivery of home and community-based services. Support the development and testing of pilot programs to improve options for people with dementia to remain at home instead of more costly Medicaid-funded long-term care services.



## **Supporting Family Caregivers**

#### **NEEDS:**

- Coordination of existing support services
- Monitor and assess existing and future 1915(c) waivers to ensure they are inclusive of the dementia population.
- Increased Access to Care Planning Services, Dementia education, and resources

# The Public Health Impact of Alzheimer's and Dementia Family Caregivers

Over 93 thousand Arkansans provide unpaid care to people with Alzheimer's or other dementias. These caregivers provimore than 139 million hours value at over \$2.2 BILLION.

\*Source: Alzheimer's Disease Facts and Figures 2022

## Profile of a Dementia Caregiver

Over 60% of caregivers are **women**.

More than half have been providing care for at least four years. 26% are 65 or older, and two-thirds are over the age of 50.

41% have a household income of \$50,000 or less.

\*Source: Alzheimer's Disease Facts and Figures 2022

#### The Impact of Caregiving on the Workforce

57%

had to go in late/leave early/take time off

8%

turned down a promotion

18%

had to go from full-time to part-time work

9%

had to quit work entirely

16%

had to take a leave of absence

7%

lost job benefits Work-Related changes experienced by Dementia Caregivers

# Supporting Family Caregivers Recommendations

- Work in coordination with state agencies and non-governmental organizations, such as the Area Agencies on Aging, the UAMS Centers on Aging, and the Alzheimer's Association, to develop and deliver no-cost training for family caregivers of people with dementia to improve the delivery of care and support better outcomes for family caregivers.
- Establish a permanent dementia-caregiver respite grant program.
  - We are currently working within a pilot program funded by the Department of Human Services to provide respite grants specific to dementia caregivers.



#### **Healthcare Workforce and Dementia**

#### **NEEDS:**

- Ensure we are preparing the healthcare and professional workforce to meet the unique needs of a rising dementia population.
- Address the healthcare workforce shortage

## Healthcare Workforce Development and Dementia Training

- Expand collaboration between the non-profit sector and the medical community to ensure they are aware of the resources available to them and to caregivers.
- Establish dementia-specific training requirements for Adult Protective Service, LTC Ombudsman, LTC Investigators and other state and local government employees serving people with dementia.
- Establish dementia-specific training requirements for members of law enforcement and first responders as part of the initial curriculum and ongoing training.



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