

**Setting a Roadmap to Address Alzheimer's in the  
Commonwealth:**

**A Report on the Assessment of the Current and  
Anticipated Future Impact of  
Alzheimer's Disease and Related Dementias  
on Kentuckians with Recommendations for Action**

**Submitted in Response to SJR 6**

**By**

**The Office on Alzheimer's Disease and Related Disorders and  
Kentucky Alzheimer's Disease and Related Disorders Advisory Council**

**Date XX, 2008**

January 15, 2008

Honorable David Williams, President, State Senate  
Honorable Jody Richards, Speaker, State House  
General Assembly, Commonwealth of Kentucky  
State Capitol, Frankfort, Kentucky

Dear President Williams and Speaker Richards,

We are pleased to submit this assessment of the current and future impact of Alzheimer's on the Commonwealth of Kentucky, as required by Senate Joint Resolution 6 passed in the 2007 Session. This report reflects the work and input of volunteer and paid stakeholders and state staff who spent seven months studying the needs of Kentuckians with Alzheimer's disease and their families, surveying state services and resources, and analyzing ways to improve the Commonwealth's response to this public health crisis.

As the large baby-boom cohort of Kentuckians enters the age of greatest risk for Alzheimer's, the impact is going to be staggering on families, on our health care system, communities, public safety and long term care resources.

We urge every member of the General Assembly to read this report: ***“Setting a Roadmap to Address Alzheimer's in the Commonwealth: A Report on the Assessment of the Current and Anticipated Future Impact of Alzheimer's Disease and Related Dementias on Kentuckians with Recommendations for Action.”***

In it, you will find that needed data and statistics about Kentucky's population with Alzheimer's are sorely lacking. So how is the Commonwealth to embark upon sound planning to address the needs of individuals and families living with this disease?

In it, you will find that there is no functioning entity within state government that can coordinate information, services or policies related to Alzheimer's and related dementias. With a badly out-dated statutory basis and insufficient resources, the Alzheimer's advisory council and office are ill-equipped to take on the important charge envisioned in this Report to continue to assess needs, establish training and practice protocols, encourage coordination among state agencies, and serve as a clearinghouse for up-to-date information and resources.

This Alzheimer's state plan includes recommendations for ways to address these issues and to enhance existing state programs, improve the quality of dementia care across the array of services, help family caregivers, and encourage research on Alzheimer's disease and care practices. We urge the General Assembly to take action with legislation as appropriate and to monitor the state government response to this report.

Respectfully submitted,

Tonya M. Cox, MSW  
Co-Chairs, State Advisory Council on Alzheimer's Disease and Related Disorders.

Jane M. Thibault, PhD

Enc.: “Setting a Roadmap to Address Alzheimer's in the Commonwealth: A Report on the Assessment of the Current and Anticipated Future Impact of Alzheimer's Disease and Related Dementias on Kentuckians with Recommendations for Action”



**CABINET FOR HEALTH AND FAMILY SERVICES  
DEPARTMENT FOR AGING AND INDEPENDENT LIVING**

275 E Main St. 3W-F  
Frankfort, KY 40621  
(502) 564-8930  
Fax: (502) 564-4595  
[www.chfs.ky.gov](http://www.chfs.ky.gov)

Steven L. Beshear  
Governor

Janie Miller  
Secretary

January 24, 2008

The Honorable Steve Beshear  
Governor of Kentucky  
700 Capitol Avenue  
Frankfort, Kentucky 40601

Dear Governor Beshear and Members of the General Assembly:

Accompanying this letter is 'Setting a Roadmap to Address Alzheimer's in the Commonwealth: A Report on the Assessment of the Current and Anticipated Future Impact of Alzheimer's Disease and Related Dementias on Kentuckians with Recommendations for Action.' This Report is submitted by the Office on Alzheimer's Disease and Related Disorders and Kentucky Alzheimer's Disease and Related Disorders Council. The Report was generated pursuant to the requirements of Senate joint Resolution 6 (SJR 6), passed and signed during the 2007 Legislative Session.

The requirements of the legislation, as stated in SJR 6, were to assess the current and future impact of Alzheimer's Disease and related dementias on Kentuckians, by examining the existing services and resources addressing the needs of persons with Alzheimer's, their families, and caregivers and, developing a strategy to mobilize a state response to this public health crisis. The Department for Aging and Independent Living (DAIL) concurs with the identified challenges and supports the recommendations to address this crisis and will pursue fulfilling the recommendations pending available funding.

Participants, on behalf of the Commonwealth, thank you and the Kentucky General Assembly for the opportunity to assess and summarize a comprehensive state strategy to address the needs of persons with Alzheimer's disease and related disorders.

Sincerely,

A handwritten signature in blue ink that reads "Deborah S. Anderson".

Deborah S. Anderson  
Commissioner

Enclosure

**Kentucky Advisory Council on Alzheimer's Disease  
Workgroups**

**Community Services**

**Nancy Addington**  
Lincoln Trail Area Agency  
on Aging  
Elizabethtown, KY

**Elisa Freeman-Carr**  
Alzheimer's Association  
Louisville, KY

**Robynn Pease, PhD**  
Work life  
University of Kentucky  
Lexington, KY

**Debra Burchett**  
United Mine Workers  
Association  
Prestonsburg, KY

**Officer Steve Gaunce**  
Project Lifesaver  
Lexington Fayette Urban  
County Government,  
Division of Police  
Lexington, KY

**Dona Renfro**  
Lexington, KY

**Rhonda Davis**  
Bluegrass Area Agency  
on Aging  
Lexington, KY

**Barbara Gordon**  
Kentuckiana Regional  
Planning & Development  
Agency  
Louisville, KY

**Representative  
Susan Westrom**  
Lexington, KY

**Bud Dixon**  
Jefferson county Search Dog  
Association  
Louisville, KY

**Debbie McCarty**  
Barren River Area Agency  
on Aging  
Bowling Green, KY

**Donna Frazier**  
Big Sandy Area Agency  
on Aging  
Prestonsburg, KY

**Bill Nighbert**  
Frankfort, KY

## **Health and Health Services**

### **Stephen Combs**

Cumberland Valley District  
Health Department  
Pineville, KY

### **Aletha Malone**

Alzheimer's Association  
Lexington, KY

### **Joseph Smith**

Kentucky Primary Care  
Association  
Frankfort, KY

### **Carol Hall**

Department for Aging and  
Independent Living  
Frankfort, KY

### **Marnie Mountjoy**

Department for Aging and  
Independent Living  
Frankfort, KY

### **Cris Sparks**

Department for Public Health  
Frankfort, KY

### **Mary Ann Hirschler**

Department for Aging and  
Independent Living  
Frankfort, KY

### **Phyllis Parker**

Department for Mental Health  
and Mental Retardation  
Services  
Frankfort, KY

### **Sue Thomas-Cox**

Department for Public Health  
Frankfort, KY

## **Long Term Care Residential**

**Alan Beuscher**  
Wesley Village  
Wilmore, KY

**Ruby Jo Cummins  
Lubarsky**  
Kentucky Association of  
Health Care Facilities  
Louisville, KY

**Charletta Parker, CNA**  
Masonic Homes of Kentucky  
Louisville, KY

**Tonya Cox**  
Alzheimer's Association  
Lexington, KY

**Margaret McCoskey**  
Liberty Ridge  
Lexington, KY

**John Underwood**  
Kentucky Association of  
Assisted Living Facilities  
Buckner, KY

**Sherry Culp**  
Nursing Home Ombudsman  
Agency of the Bluegrass  
Lexington, KY

**Judy Montfort**  
Division of Long-Term Care  
Frankfort, KY

**Kathy Wiederhold**  
Masonic Homes of Kentucky  
Louisville, KY

**Keith Knapp, PhD**  
Christian Care Communities  
Louisville, KY

**Nancy Orr-Rainey**  
Louisville, KY

**Ray Dickson**  
Kentucky Association of  
Not-for-Profit Homes and  
Services for the Aging  
Louisville, KY

## Long Term Care Home & Community Based Care

**Nancy Addington**

Lincoln Trail Area Agency  
on Aging  
Elizabethtown, KY

**Tonya Cox**

Alzheimer's Association  
Lexington, KY

**Karen Hinkle**

Kentucky Home Health  
Association  
Lexington, KY

**David Bassoni**

Bluegrass Area Agency  
on Aging  
Lexington, KY

**Phyllis Culp**

Department for Aging and  
Independent Living  
Frankfort, KY

**Karen Robinson**

University of Louisville,  
School of Nursing  
Louisville, KY

**Bruce Carver**

Pennyrile Area Agency on  
Aging  
Hopkinsville, KY

**Joe Evanko**

Alzheimer's Support Group  
Leader  
Mayfield, KY

**Kay Williams**

The Kentucky Association of  
Hospice and Palliative Care  
& Lourdes Hospital  
Paducah, KY

## **Disease Background**

**Arlene Johnson**  
University of Kentucky  
Council on Aging  
OVAR/GEC  
Lexington, KY

**Steve Olding**  
Alzheimer's Association  
Cincinnati, OH

**Mike Smith, PhD**  
University of Kentucky  
College of Public Health  
Lexington, KY

**Ellen Kershaw**  
Alzheimer's Association  
Louisville, KY

## **Research**

**Roberta Davis**  
Alzheimer's Disease Center  
Sanders-Brown Center on  
Aging, University of  
Kentucky  
Lexington, KY

**Fred Schmitt, PhD**  
Alzheimer's Disease Center  
Sanders-Brown Center on  
Aging, University of  
Kentucky  
Lexington, KY

**Dr. Jane Thibault, PhD**  
Family & Geriatric Medicine  
University of Louisville  
Louisville, KY

**Dr. Greg Jicha, MD, PhD**  
Alzheimer's Disease Center  
Sanders-Brown Center on  
Aging, University of  
Kentucky  
Lexington, KY

**Ben Schoenbachler, M.D.**  
University of Louisville,  
Department of Psychiatry and  
Behavioral Sciences  
Louisville, KY

**Deborah Danner, PhD**  
Alzheimer's Disease Center  
Sanders-Brown Center on  
Aging, University of  
Kentucky  
Lexington, KY



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## EXECUTIVE SUMMARY

Alzheimer's Disease is the seventh leading cause of death for people in the United States and the fifth leading cause of death for those over the age of 65. In 2000, approximately 74,000 Kentuckians age 65 and over were diagnosed with Alzheimer's Disease and that number is expected to rise to 80,000 by 2010. According to the Alzheimer's Association, it is estimated that 70% of people with Alzheimer's and other dementias live at home receiving care by family and friends and 70% of nursing home residents have some degree of cognitive impairment. The fragmented and out-dated resources, information, and services available in Kentucky will further impede the state's responses to the Alzheimer's Disease epidemic.

Addressing the need to provide viable resources to adequately care for persons with Alzheimer's Disease and the growing number of individuals who will most likely develop this disease in the future, Senate Joint Resolution 6 (SJR 6) (Appendix B) directed the Office on Alzheimer's Disease and Related Disorders and the Alzheimer's Disease and Related Disorders Advisory Council to assess the current and future impact of Alzheimer's disease on Kentuckians and State systems, programs, and services. In the following three chapters, this report presents the results of the assessment, issues and challenges, corresponding recommendations, and strategies to implement change.

Following is an abbreviated summary of each chapter along with global recommendations. Specific strategies to address the recommendations can be found in the next section, Recommendations and Corresponding Strategies, as well as in Chapter 3. Following each strategy is an estimated date of completion. Recommendations are in no particular order of priority and are summarized in the order they appear in the report.

### **Chapter 1:**

Chapter 1 includes an overview of the organization of the report as well as the trends, symptoms, warning signs, stages, and prevalence estimates related to Alzheimer's Disease.

### **Major Alzheimer's Disease Findings:**

- Families may notice warning signs of Alzheimer's Disease in a loved one but may relegate them to "normal aging". Physicians may also miss these early signs of the disease.
- Alzheimer's Disease typically develops slowly and causes a gradual decline in cognitive abilities, usually over a span of seven to 10 years. It eventually affects nearly all brain functions, including memory, movement, language, behavior, judgment and abstract reasoning. These changes impact the victim's ability to care for himself/herself, as daily living skills are gradually lost over the course of this disease.
- While each individual is different, the progression of his or her disease can be roughly divided into mild, moderate, and severe stages.
- According to the Alzheimer's Association, it is estimated that 70% of people with Alzheimer's and other dementias live at home receiving care by family and friends and 70% of nursing home residents have some degree of cognitive impairment.

- There is consensus in the research fields that this disease is linked to several changes in the brain's metabolism, resulting in abnormal brain structures called plaques and tangles. Plaques contain deposits of an abnormal protein fragment called beta-amyloid that builds up between cells much like plaque on the teeth. As tangles develop in the brain due to changes in the tau protein, brain cells lose their ability to work normally and eventually die.
- An estimated 5.1 million Americans have Alzheimer's disease in 2007. This number includes 4.9 million people age 65 and older and at least 200,000 individuals younger than 65 with early-onset Alzheimer's.
- According to the Alzheimer's Association, "The greatest risk factor for Alzheimer's is increasing age, and with 78 million baby boomers beginning to turn 60 last year, it is estimated that someone in America develops Alzheimer's every 72 seconds; by mid-century someone will develop Alzheimer's every 33 seconds.
- Currently, very little information exists regarding demographics for AD and ethnicity groups in Kentucky.
- There is no cure for Alzheimer's but treatments for symptoms, combined with the right services and support, can make life better for those who have the disease and their caregivers.

## **Chapter 2:**

Chapter 2 provides a summary of the current and future impact of Alzheimer's Disease and related disorders as it relates to Kentucky's role and State infrastructure including existing services, programs, and State support of Alzheimer's research, and other resources.

### **Major State Role and Infrastructure Findings:**

- Realizing the imminent problem of age related neurodegenerative diseases, the 2000 Kentucky legislature created by statute (KRS 194A.601), the Office of Alzheimer's Disease and Related Disorders; however, the Office was established without any funding.
- Kentucky Department for Aging and Independent Living (DAIL) was established in December of 2006. DAIL administers programs and service, establishes policy and advocates on behalf of Kentucky's elders and people with disabilities.
- In partnership with Kentucky's 15 Area Agencies on Aging and community partners to provide needed services and programs, DAIL is focused on addressing issues and circumstances that stand in the way of elders and people with disabilities achieving the best possible quality of life.
- DAIL helps streamline processes and provides one-on-one assistance by phone through the Kentucky Resource Market, using a one-call-does-it all approach for elder Kentuckians; DAIL assists clients by finding the most individualized appropriate information, services, or program.

### **Major Services and Program Findings:**

- Alzheimer's is not a stand-alone disease but often resides in an individual with other major co-morbid chronic diseases. There is a drastic increase in cost for facility placement of individuals with a chronic disease and Alzheimer's.

- State and federal Medicaid spending for nursing home care for people with Alzheimer's and other dementias was estimated at \$21 billion in 2005. It is projected to increase to \$24 billion in 2010 and \$27 billion in 2015.
- There are only 10 geriatric Psychiatrists in Kentucky with rural areas in both eastern and western Kentucky underserved by all specialty medical services.
- There are currently 313 nursing home facilities in Kentucky.
- There are currently 100 certified assisted living facilities and of those, 12 have special dementia units with locked doors. Regulations limit the use of Assisted Living to individuals in the early or mid stages of the disease. Additionally, Kentucky regulations prohibit the administration of medications or any other medical care in Assisted Living facilities.
- Costs to business for employees who are caregivers of people with Alzheimer's and other dementias amount to \$36.5 billion. These costs result from lost productivity, missed work and costs to replace workers who leave their jobs to meet the demands of caregiving.
- The Adult Day/Alzheimer's Disease Respite Program was created in statute (KRS 205.950) in 1992. Currently, it is the only Alzheimer's Disease specific program in Kentucky serving approximately 700 individuals.
- There are 65 counties in Kentucky without any Adult Day Centers and 45 counties with only one Adult Day Center.
- Currently, there is a total of 3,872 on the waiting list for state funded home care services. Of this number, 1,079 are waiting on home delivered meal services and 113 are waiting on respite services.

### **Major Research Findings:**

- Of the total 29 Alzheimer's Disease Centers funded by National Institutes on Aging, one exists in Kentucky, University of Kentucky's Sanders-Brown Center on Aging. Research at Sander-Brown focuses on developing an understanding of age-related diseases including Alzheimer's Disease (AD), stroke, and prion diseases (e.g. mad cow and wasting diseases).
- In 1989, the State Legislature designated \$244,000 to support three AD research positions within UK's Sanders-Brown Center on Aging. This investment has helped return over \$40 million to Kentucky in the form of research grants and should be expanded.
- In 2000, the Gheens Center for Aging and Age-Related Diseases was established in University of Louisville's (U of L) School of Medicine with a \$2.5 million gift from the Gheens Foundation.
- Both UK and U of L recruit Kentuckians for studies focusing on brain changes as it relates to aging. The longitudinal Biological Resilient Adults in Neurological Studies (BRAiNS) and autopsy services for confirmation of diagnosis are key elements of the UK program.
- \$100,000 of state general funds was budgeted across fiscal years 2007 and 2008 for DAIL to partner with the Alzheimer's Association and UNC Chapel Hill to explore the effectiveness of dementia training in 6 long-term care facilities.
- Unlike states such as California and Florida, Kentucky does not have any targeted funds for AD research for Kentucky's unique population. This limits Kentucky's

- ability to provide adequate clinical care for its elders and limits research grant competitiveness at the national level.
- During the past year, DAIL has secured approximately \$1.2 million in grants and often partners with University researchers and Alzheimer’s Association trainers to implement and evaluate practices.
  - The Administration on Aging currently lists 7 training curriculums as evidence-based practices. Most of the training components are delivered to the family caregiver of an individual with Alzheimer’s Disease or Related Dementias.
  - Through one of DAIL’s secured grants, staff will partner with the Alzheimer’s Association and Sander’s Brown to evaluate the Kentucky-grown “Best Friends Approach to Dementia Care” a model widely used by other states as well as internationally. Although the model may be a promising practice or an evidence based practice, until now, the anecdotal benefits of this program have not been empirically tested.

### **Chapter 3:**

Chapter 3 details the identified issues or challenges and corresponding recommendations designed to improve state role and infrastructure, programs and services, and research and evaluation.

#### **Major State Role and Infrastructure Issues or Challenges:**

- Initiatives addressing services and supports for individuals with Alzheimer’s cross many agencies and organizations.
- The Office on Alzheimer’s Disease and Related Disorders was created by statute (KRS 194A.601) in 2000; however, there was no funding for this Office and the duties ascribed to it were absorbed into the Office of Aging (now DAIL) by utilizing existing staff.
- The Kentucky Department for Aging and Independent Living does not require diagnostic data to be reported. Thus there is no conclusive information on the number of individuals who are being served with Alzheimer’s in either the State general funded Homecare program or the Older Americans Act programs.
- The current array of institutional care options is rigidly sub-divided based on providers’ service capabilities rather than on the changing needs of individuals; this is particularly problematic for persons with dementia because of their reliance on environmental consistency and reduced capacity for processing change.
- Unlike auto, home, disability, life or health insurance, long term care insurance is not widely perceived as a normal life risk to protect against with insurance; people mistakenly over-rely on Medicare and Medicaid to meet any long term care needs they may have in the future.
- Institutional environments are typically grounded in a “medical model” of care, and current regulations governing facility design and service reimbursement have the unintended effects of preserving the status quo and inhibiting innovation.

**Recommendation 3.1:** Revise KRS 194A.601 to make the Office a viable, fully funded and staffed entity within the Department for Aging and Independent Living working in conjunction with the Council.

**Recommendation 3.2:** Increase and improve support for family caregivers.

**Recommendation 3.3:** Develop, implement and coordinate a statewide data collection system.

**Recommendation 3.4:** Develop and implement training on Alzheimer's and Related Dementias for various stakeholders.

**Recommendation 3.5:** Establish State Protocol on Appropriate Interface and Choices for Individuals with Alzheimer's and Related Dementias and Their Families.

**Recommendation 3.6:** Explore options to increase insurance coverage for individuals with Alzheimer's and Related Dementias.

**Major Existing Program and Services Issues or Challenges:**

- Care providers (physicians, nurses, therapists, nursing assistants, psychologists, social workers) and regulators (enforcement officials) frequently operate with insufficient, incomplete and/or outdated information about diagnosing, effective treatment options and forming appropriate goals of care for persons with chronic, progressive memory-impairing conditions.
- Behavioral challenges often exceed long-term care providers' capability; interest or perceived liability; admission and discharge criteria may be more provider-protective than resident-centered.

**Recommendation 3.7:** Institute State policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer's and Related Dementias Related Disease.

**Major Research and Evaluation Issues or Challenges:**

- Currently there is no known use in Kentucky of any of the 7 evidence-based training curricula/practices for family caregivers recognized by the U.S. Administration on Aging in Kentucky.
- Kentucky does not have any targeted funds to support Alzheimer's Disease research through Kentucky universities or other research and evaluation activities such as the implementation of evidence based practices, evaluation of evidence based practices specific to Kentucky populations and exploration of promising practices that may currently exist in the State.

**Recommendation 3.8:** Explore the designation of existing state funding supports of Alzheimer's research through Kentucky universities and other resources.

**Recommendation 3.9:** Establish policies, procedures, and incentives to incorporate evidence-based practices into training, service, and program activities.

**Recommendation 3.10:** Research and evaluate promising practices across various regions in Kentucky.

## RECOMMENDATIONS AND STRATEGIES

### State Role and Infrastructure

#### Recommendation 3.1

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*Revise KRS 194A.601 to make the Office a viable, fully funded and staffed entity within the Department for Aging and Independent Living working in conjunction with the Council.*

##### Strategies:

- 3.1.1. Recreate the “office” to become the Alzheimer’s Disease and Related Dementias Unit working in conjunction with the Council. (2008)
- 3.1.2. Obtain specific State general funding to hire a full time coordinator and 2 FTE program staff for the Alzheimer’s and Related Dementias Unit. (2008)
- 3.1.3. Expand the role of the Unit to include policy, research and coordination of services. (2008)
- 3.1.4. Require the Unit to conduct the following activities: (2008)
  - Disseminate information on services and related activities for individuals with Alzheimer’s disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public.
  - Enhance the DAIL website to include Alzheimer’s information and links.
  - Establish a strategy to link and coordinate services and activities of State agencies, other service providers, advocacy groups and other entities throughout the State such as emergency personnel, police, universities and attorneys and other staff associated with the legal system.
  - Coordinate and provide support for Council activities.

#### Recommendation 3.2

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*Increase and improve support for family caregivers*

##### Strategies:



- 3.2.1. Request an increase in the Alzheimer’s Respite Services line item in the State budget. (2008)
- 3.2.2. Utilize the Council and stakeholder community to revise the current definition, eligibility and service requirements for the provision of respite. (2008)
- 3.2.3. Ensure a system of care coordinators and benefit counselors in each of the 15 ADD regions. (2010)
- 3.2.4. Develop incentives beyond tax incentives for caregivers. (2010)
- 3.2.5. Support legislation for a caregiver tax credit for people who provide in-home care for dependent relatives who have little to no income, and have been diagnosed with Alzheimer’s Disease and related dementias. (2008)
- 3.2.6. Develop a demonstration to test the feasibility and cost-effectiveness of adult day care clients receiving services in other long- term care settings traditionally considered “institutional” in order to expand access and accommodate anticipated growth in demand. (2009)

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### **Recommendation 3.3**

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*Develop, implement and coordinate a statewide data collection system.*

**Strategies:**

- 3.3.1. Require the Alzheimer’s and Related Dementias Unit to coordinate a statewide effort to develop, and implement a statewide data collection system. (2009)
- 3.3.2. Collect data and monitor at a minimum the following data: (2010)
  - a. The prevalence of dementia related diseases across the Commonwealth;
  - b. The prevalence of dementia related diseases by county;
  - c. The prevalence of early onset dementia and related diseases across the Commonwealth;
  - d. The prevalence of inpatient geriatric psychiatry beds;
  - e. The availability of geriatric services and specialists;
  - f. The availability of dementia related services and supports;
  - g. The availability of assessment services for Alzheimer’s and related dementias;

- h. The number and location (county) of Kentuckians who are currently providing care in their home to a family member.

### **Recommendation 3.4**

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*Develop and implement training on Alzheimer's and Related Dementias Related Disorders for various stakeholders.*

#### **Strategies:**

- 3.4.1. Identify specific training resources for targeted audiences across the state. (2009)
- 3.4.2. Develop relationships with police and community partners to develop and implement training (such as, but not excluding including but not limited to, bankers, attorneys, police, emergency personnel, etc.). (2009)
- 3.4.3. Develop and implement an evidence-based training curriculum and implementation strategies for targeted audiences (i.e. Department for Mental Health and Mental Retardation, Office of Inspector General surveyors, Comprehensive Care Centers, family caregivers, etc.). (2009)
- 3.4.4. Develop and implement an evidence-based training curriculum and implementation strategies for Long Term Care facilities. (2009)
- 3.4.5. Require mandatory dementia-specific training as part of DOCJT yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers). (2009)
- 3.4.6. Require mandatory dementia-specific training for emergency room staff including nurses, physicians and related services technicians such as radiology. (2009)
- 3.4.7. Increase training for state adult protective services workers on Alzheimer's/dementia. (2009)
- 3.4.8. Require training for providers and State staff associated with any of the Medicaid home and community based waivers. (2010)
- 3.4.9. Develop a portable certification program for para-professional direct caregivers with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer's and related dementias. (2010)
- 3.4.10. Work with the universities to develop specific training and recruitment options including:

- a. The development of optimal training content standards for licensed health professionals; target Kentucky’s professional schools to integrate it into curricula. (2010)
- b. Create a “Bucks for Brains” program to recruit and train geriatric psychiatrists, geriatricians, and other geriatric specialists. (2012)
- c. The development of residencies or fellowships for training of geriatric psychiatrists, geriatricians, and other geriatric specialists.. (2012)
- d. The development of a specific track on Alzheimer’s disease related dementias and dementia related diseases for medical students and residents. (2012)

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**Recommendation 3.5**

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*Establish State Protocol on Appropriate Interface and Choices for Individuals with Alzheimer’s and Related Dementias and Their Families.*

**Strategies:**

- 3.5.1. Require the Unit and Council to develop a protocol detailing how to interface with individuals with Alzheimer’s and related dementias and their families. The protocol should include appropriate placement care options based on the stages of Alzheimer’s and related dementias. (2008)
- 3.5.2. Require the Unit and DAIL to provide training to staff within the Cabinet for Health and Family Services on the protocol including but not limited to adult protective services workers, guardianship/social workers, and staff from the Office of Inspector General and the Department for Mental Health and Mental Retardation on the protocol. (2009)
- 3.5.3. Require, through the Secretary of the Cabinet, that all Department staff utilize the protocol as an established Cabinet practice. (2009)

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**Recommendation 3.6**

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*Explore options to increase insurance coverage for individuals with Alzheimer’s and Related Dementias.*

**Strategies:**

- 3.6.1. Explore changes needed to ensure Medicaid eligibility for individuals with early onset Alzheimer’s Disease or Related Dementias. (2009)

- 3.6.2. Explore potential for Medicaid waiver specific to Alzheimer’s Disease and Related Dementias. (2009)
- 3.6.3. Explore services and options available under private insurance entities. (2009)
- 3.6.4. Provide tax incentives for individuals who purchase long-term care insurance. (2008)
- 3.6.5. Support the establishment of a Kentucky Long-Term Care Partnership Insurance Program. This partnership has been successfully piloted in California, Connecticut, Indiana, and New York. (2008)
- 3.6.6. Advocate for integrated systems of healthcare and support that are effective for individuals with Alzheimer’s disease or related dementias and their families. (e.g. disease management strategies, practice guidelines, home and community based care, hospice care and chronic care management). (2008)
- 3.6.7. Require mental health parity. (2008)
- 3.6.8. Promote educational resources for better understanding Long Term Care financing. (2008)

## **Programs and Services**

### **Recommendation 3.7**

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*Institute state policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer’s Disease and Related Dementias.*

#### **Strategies:**

- 3.7.1 Work with law enforcement to implement a coordinated protocol or swift and appropriate action upon report of a missing adult with dementia. (2009)
- 3.7.2 Offer tax credits to families for the purchase of locator devices. (2009)
- 3.7.3 Direct the Council to study new technologies that can help locate missing persons and to make recommendations about implementation strategies. (2010)
- 3.7.4 Utilize the Council to evaluate state regulations on home care, adult day and home health to assure they are “dementia friendly”. (2008)
- 3.7.5. Explore changes in the certificate of need requirements in order to foster expansions of Alzheimer’s and dementia specific services. (2009)

- 3.7.6. Develop a process/protocol to permit persons with dementia to remain in their current living environment despite a change in their condition (e.g. challenging behaviors or other disease symptom) that under existing regulations might otherwise promote their move to a different level of care; this protocol should assure that the provider can adequately demonstrate that the person's care needs can be safely and effectively met without the disruption of moving. (2009).
- 3.7.7. Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior. (2008)
- 3.7.8. Develop regulations or waiver protocol inviting the development of new approaches to facility design that are preserve resident safety, recognize the special needs of persons with memory loss and pursuant to evidence based practice show promise for improving the quality of their lives. (2009)
- 3.7.9. Review the current Kentucky Medicaid programs to ensure "dementia friendly" approaches and policies. (2008)
  - a. Review the "Resource Utilization Groups" (RUGs) system to determine values of behavior management and evidenced based interventions.
  - b. Increasing opportunities for self-determination.
  - c. Identify challenges to admission and eligibility requirements.
- 3.7.10. Review overlapping requirements for licenses for personal care homes and assisted living facilities such as medication management including oversight, assistance, administration and monitoring and recommend appropriate regulation changes to accommodate the needs of persons with dementia. (2010)

## Research and Evaluation

### Recommendation 3.8

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*Explore the designation of existing state funding supports of Alzheimer’s research through Kentucky universities and other resources:*

#### Strategies:

- 3.8.1 Explore processes for distributing state funds to University faculty and determine feasibility of designating state funds specifically toward Alzheimer’s research. (2009)
- 3.8.2 Explore additional funding sources for Alzheimer’s research through Kentucky universities and other resources. (2009)

### Recommendation 3.9

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*Establish policies, procedures, and incentives to incorporate evidence-based practices into dementia-specific training, service, and program activities.*

#### Strategies:

- 3.9.1. Identify and promote wide use of evidence based practices through the development of an Evidence-Based Practice Guide specific to Alzheimer’s Care. (2008)
- 3.9.2. Explore changes needed to support the purchase and provision of evidence based practice training and education. (2008)
- 3.9.3. Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds. (2009)
- 3.9.4 Identify and explore ways to further evaluate existing evidence based practices with Kentucky’s populations. (2008)

### Recommendation 3.10

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*Research and evaluate promising practices across various regions in Kentucky.*

#### Strategies:

- 3.10.1. Continue exploring grant opportunities to provide empirical evidence of nationally recognized evidence based practices as well as practices that are already occurring in the state (e.g., Best Friend’s model of care). (2008)

## **CHAPTER 1: INTRODUCTION**

### **Organization of the Report**

This report includes three chapters. Chapter 1 includes an introductory overview of Alzheimer's Disease (AD) (Appendix A to this Report sets forth a Glossary of Terms) including trends and population needs, warning signs on AD, stages of AD and prevalence estimates. Chapter 2 provides an overview of existing services, resources, and the capacity of Kentucky's state infrastructure to meet the needs of the increasing population with AD. Chapter 3 details identified challenges and corresponding recommendations to address the short-term and long-term needs of individuals with Alzheimer's and the increasing number of persons who will most likely develop the disease. Strategies to implement recommendations are also provided.

### **Trends in Alzheimer's Populations and Needs**

Alzheimer's Disease is a progressive and terminal disease that destroys cells in the brain. It is the loss of brain cells that causes the loss of memory, distorted thinking and behavior changes that, in turn, affect the person's ability to work, enjoy hobbies, and social activities. The disease is progressive and the outcome is always fatal.

### **Alzheimer's Disease**

Alzheimer's Disease (AD) is the most common form of the brain diseases listed under the major category of dementia. Dementia occurs in people with AD because healthy brain tissue degenerates, causing a steady decline in memory, mental abilities, and daily living skills. AD is a progressive, degenerative brain disease that causes more than simple forgetfulness. It may start with slight memory loss and confusion, but it eventually leads to irreversible mental impairment that destroys a person's ability to remember, reason, learn and imagine.

Symptoms common in early-stages include the first indications of memory loss, lapses in judgment, changes in personality, and the inability to follow through with common life tasks. Families may notice these changes but may relegate them to "normal aging". Physicians may also miss these early signs of the disease. These individuals usually require minimal assistance with normal activities of daily living such as cooking, dressing and cleaning. By the time a diagnosis is made the individual is most commonly past the early-stages. This delay in diagnosis is unfortunate since many medications currently available to treat the disease appear to work best in the early stages by providing some symptomatic relief and may also delay further deterioration of the brain and subsequent memory. Early stage often refers to individuals, irrespective of age, who are diagnosed during the early onset or early stages of the disease. Although most individuals experience the onset of stages at age 65 or older, there are also occurrences of the disease in persons under the age of 65 and younger, including persons in their early thirties, forties or fifties. Early on-set refers to individuals who develop dementia prior to age 65.

There is currently no cure for AD but researchers have made progress in the last 10 years with treatment and identification. Treatment for symptoms combined with the right services and support can make life better for those who have the disease and their caregivers. Treatments primarily improve the quality of life for some people with AD and as more drugs are being studied, scientists have discovered several genes associated with Alzheimer's, which may lead to new treatments to block progression of this complex disease. There is consensus in the research fields that the disease is a combination of changes in the brain cells that are called plaques and tangles. Plaques contain abnormal protein deposits called beta-amyloid that builds up between cells. Tangles are twisted fibers of another protein called tau. Tau causes twisted strands inside the nerve cell and both lead to cell death.

### **Warning Signs of Alzheimer's Disease:**

Because early Alzheimer's symptoms progress slowly, diagnosis is often delayed. People developing the condition may be frighteningly aware of their problems but careful to keep them hidden, refusing to see a doctor. As a result, even their families may fail to see what's going on. When the signs and symptoms are too obvious to miss, those closest to the person often realize that similar, but less severe, difficulties have been present for years. Contributing to the complexity of AD, normal aging processes may be mistaken for warning signs. Considering the potential confusion in regards to normal aging versus signs of AD, the Alzheimer's Association has provided the following warning signs of AD along with normal aging characteristics:

*Memory loss.* Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later. *What's normal? Forgetting names or appointments occasionally.*

*Difficulty performing familiar tasks.* People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game. *What's normal? Occasionally forgetting why you came into a room or what you planned to say.*

*Problems with language.* People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for "that thing for my mouth." *What's normal? Sometimes having trouble finding the right word.*

*Disorientation to time and place.* People with Alzheimer's disease can become lost in their own neighborhood, forget where they are and how they got there, and not know how to get back home. *What's normal? Forgetting the day of the week or where you were going.*

*Poor or decreased judgment.* Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment, like giving away large sums of money to telemarketers. *What's normal? Making a questionable or debatable decision from time to time.*



*Problems with abstract thinking.* Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are for and how they should be used. *What's normal? Finding it challenging to balance a checkbook.*

*Misplacing things.* A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl. *What's normal? Misplacing keys or a wallet temporarily.*

*Changes in mood or behavior.* Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason. *What's normal? Occasionally feeling sad or moody.*

*Changes in personality.* The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member. *What's normal? People's personalities do change somewhat with age.*

*Loss of initiative.* A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities. *What's normal? Sometimes feeling weary of work or social obligations.*

## **Stages of Alzheimer's Disease**

Alzheimer's disease typically develops slowly and causes a gradual decline in cognitive abilities, usually over a span of seven to 10 years. It eventually affects all brain functions, including memory, movement, language, behavior, judgment and abstract reasoning. Not everyone will experience the same symptoms or progress at the same rate. The rate of progression varies widely among individuals. For some, severe dementia occurs within five years of diagnosis. For others, it can take more than a decade. On average, people with Alzheimer's live for eight to 10 years after diagnosis. Some live as long as 20 years.

While each individual is different, the progression of his or her disease can be roughly divided into mild, moderate, and severe stages. In order to identify symptoms and to assist in identifying what services individuals and caregivers may need, the Alzheimer's Association provides the following stage categories:

**Stage 1: No impairment (normal function).** Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

**Stage 2: Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease).** Individuals may feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

**Stage 3: Mild cognitive decline. (Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms).** Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates.
- Decreased ability to remember names when introduced to new people.
- Performance issues in social or work settings noticeable to family, friends or co-workers.
- Reading a passage and retaining little material.
- Losing or misplacing a valuable object.
- Decline in ability to plan or organize.

**Stage 4: Moderate cognitive decline (Mild or early-stage Alzheimer's disease).** At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events.
- Impaired ability to perform challenging mental arithmetic-for example, to count backward from 75 by 7s.
- Decreased capacity to perform complex tasks, such as planning dinner for guests, paying bills and managing finances.
- Reduced memory of personal history.
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations.

**Stage 5: Moderately severe cognitive decline (Moderate or mid-stage AD).** Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated.
- Become confused about where they are or about the date, day of the week or season.
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s.
- Need help choosing proper clothing for the season or the occasion.
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children.
- Usually require no assistance with eating or using the toilet.

**Stage 6: Severe cognitive decline (Moderately, severe, or mid-stage AD).** Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings.
- Recollect their personal history imperfectly, although they generally recall their own name.
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces.
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet.
- Experience disruptions of their normal sleep/waking cycle.
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly).
- Have increasing episodes of urinary or fecal incontinence.
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding.
- Tend to wander and become lost.

**Stage 7: Very severe cognitive decline (Severe or late-stage AD).** This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered.
- Individuals need help with eating and toileting and there is general incontinence of urine.
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up.
- Reflexes become abnormal and muscles grow rigid.
- Swallowing is impaired.

## **Prevalence Estimates**

More than 5 million older Americans have Alzheimer's and this number is expected to triple by the year 2050 as the population ages. AD is the seventh leading cause of death for people in the United States; and the fifth leading cause of death for those over the age of 65. Additional

estimates have placed the number somewhat higher or lower, but it is clear from all available data that Alzheimer's is a significant disease in an aging population.

By age group, the proportion of the 4.9 million Americans age 65 and over with Alzheimer's disease are as follows (Alzheimer's Disease Facts and Figures 2007, Alzheimer's Association)\*:

- 65-74 yrs.: 2%
- 75-84 yrs: 19%
- 85 + yrs. 42%+

\*Note: "These figures reflect the total number of Americans estimated to have Alzheimer's, whether or not they have ever been diagnosed with the disease. Many people with Alzheimer's and other dementia have not been diagnosed and even if they have, their diagnosis may not be noted in their medical record. These numbers are based on several studies of incidence converted to prevalence, with adjustments." (Alzheimer's Disease Facts and Figures, 2007)

The Alzheimer's Association estimates that between 2000 and 2010 there will be an eight percent increase of Kentuckians age sixty-five and older who will acquire AD. By 2025, there will be 94,000 Kentuckians with Alzheimer's, a 27 % increase from year 2000. This dramatic increase is a result of the large proportion of Kentucky's population "baby boomers" reaching age 65+; this proportion will increase as the baby boomers reach the age of highest risk. By 2030, that number is expected to rise to more than 111,000.

Currently, very little information exists regarding demographics for AD and ethnicity groups in Kentucky. According to the Centers for Disease Control and Prevention, in 2003, 1,072 Kentuckians died due to AD (National Vital Statistics Report, 2006); however, this statistic is reflective of the death certificate record of which AD is believed to be under-reported as the cause of death. The number of persons with Alzheimer's is not reliably reported, because the disease is not a mandated reportable, autopsies are not routine, and it is often undiagnosed. According to the Alzheimer's Association, it is estimated that 70% of people with Alzheimer's and other dementias live at home receiving care by family and friends and 70% of nursing home residents have some degree of cognitive impairment.

## **CHAPTER 2: CURRENT AND FUTURE IMPACT**

This chapter provides a current overview of the state role and infrastructure supporting individuals with AD, a summary of existing services including type, cost, and availability, and finally, a summary of research and evidence based practices for family caregivers.

### **State Role and Infrastructure**

Initiatives addressing services and supports for individuals with Alzheimer's cross many agencies and organizations. The following agencies provide lead roles for the integration, development, and coordination of strategies to address the needs of the current and future needs of individuals with AD: Kentucky Department for Aging and Independent Living, Office on Alzheimer's Disease and Related Disorders, and the Alzheimer's Disease and Related Disorders Advisory Council. Planning initiatives supporting the needs of individuals with AD included the following: Health Kentucky 2010, the Cabinet for Health and Family Services Plan, and the State Plan on Aging.

### **Kentucky Department for Aging and Independent Living**

Kentucky, like many other states, is making a concerted effort to rebalance its long-term care service system by reducing institutionalization and increasing opportunities for people to experience meaningful lives in the community. In an attempt to better coordinate these fragmented activities, the Kentucky Department for Aging and Independent Living (DAIL) was established in December of 2006.

DAIL administers programs and service, establishes policy and advocates on behalf of Kentucky's elders and people with disabilities. DAIL works to support and enhance freedom of choice and independence. In partnership with Kentucky's 15 Area Agencies on Aging and community partners to provide needed services and programs, DAIL is focused on addressing issues and circumstances that stand in the way of elders and people with disabilities achieving the best possible quality of life.

*DAIL Mission and Vision Statement:*

The Department for Aging and Independent Living (DAIL) takes every opportunity to provide programs and services to preserve individual dignity, self respect, and independence on behalf of Kentucky's elders and people with disabilities. DAIL pledges to focus on issues and circumstances that create barriers to quality-of-life improvements for Kentucky's seniors and people with disabilities and to remove those barriers whenever possible.

Because locating, understanding, and accessing public programs and services can be difficult, DAIL helps streamline processes and provides one-on-one assistance by phone. Through the Kentucky Resource Market, one-call-does-it all services for elder Kentuckians, DAIL assists

clients by finding the most appropriate program and service for their needs. More specifically, the Kentucky Resource Market provides information about and access to information, resources and referrals regarding mental health issues, elder abuse, mental retardation, substance abuse, transportation, consumer relations, and long-term care planning.

Kentucky's overarching vision and guiding principles for rebalancing its long-term care system mirror that of the Centers for Medicare and Medicaid's plan for long-term care reform ([http://www.cms.hhs.gov/MedicaidGenInfo/07\\_LTCReform.asp#TopOfPage](http://www.cms.hhs.gov/MedicaidGenInfo/07_LTCReform.asp#TopOfPage)). Drafted by members of the Long-Term Living Policy Initiative, Kentucky's vision is one in which "funds and programs in the public and private sector are streamlined in a single system to enable easy consumer access, a full continuum of services to match consumer needs, and delivery of quality services in a timely manner". This vision statement, built upon a person-centered philosophy of care, is indicative of a system in which the needs of the individuals drive the organization of the system rather than the settings in which care is delivered. The operationalization of this long-term care vision is guided by the following principles:

- Consumers are served in the least restrictive setting appropriate to their needs.
- Choice and independence are optimized.
- An adequate workforce is in place.
- Interventions and supports are built upon consumer and family strengths and abilities.
- Coordinated, high quality care is provided.
- The system is flexible to allow consumers to move through the continuum as needs change.
- The system is financially sustainable.
- Health information technology is optimally utilized.

Consumer Direction allows individuals to have more of a say in how they receive medical care. The Association of Aging perceives consumer direction as a way to provide long-term care for future generations. Kentucky focuses on the cash and counseling Consumer Directed Option that allows Medicaid recipients receiving Home and Community Based, Supports for Community Living, and Acquired Brain Injury waiver services to train, hire, and fire their own employees. An Alzheimer's patient who is in the early stages of the disease and still has the mental capacity to self-direct could consumer direct personally. An Alzheimer's patient, who is in the later stages of the disease and has lost the mental capacity to self-direct, can consumer direct through the use of a personal representative who has been either chosen by the consumer or has been court-appointed.

### **Alzheimer's Association**

The Commonwealth is currently served by two chapters of the national Alzheimer's Association. The Greater Kentucky and Southern Indiana Chapter of the Alzheimer's Association serve all but nine (9) counties in Northern Kentucky in addition to twelve (12) counties in Indiana. The Northern Kentucky Counties are part of the Greater Cincinnati Chapter. Both chapters are represented on the Council.

## **Office on Alzheimer’s Disease and Related Disorders**

The Office on Alzheimer’s Disease and Related Disorders was created by statute (KRS 194A.601) on July 14, 2000. It was to be a part of the Cabinet for Health Services with the purpose of “overseeing information and resources related to policy and services affecting sixty thousand (60,000) residents of Kentucky with dementia, and the caregivers and families of the residents.”

The Office was to have a Director and was to report back to the Interim Joint Committee on Health and Welfare by September 30, 2000. Duties for the Office are included in the Statute in Appendix A. There was however, no funding for this Office and the duties ascribed to it were absorbed into the Office of Aging Services by utilizing existing staff.

### **Alzheimer’s Disease and Related Disorders Advisory Council:**

The same Legislation created the Alzheimer’s Disease and Related Disorders Advisory Council. The Council was to provide recommendations to the Office, elect a chair, select the Office Director establish goals and evaluate services and supports for those individuals and families dealing with this terminal disease. The membership of the Council was delineated in the statute to include representation from three (3) agencies of state government, three (3) from local health departments, one (1) from the University of Kentucky Alzheimer’s Disease Research Center at Sanders-Brown Center on Aging, one from each of the chapters of the Alzheimer’s Association serving the Commonwealth with the remainder of the fifteen (15) representing consumers, health care providers, and the medical research community. All members are appointed by the Governor’s office.

The Commonwealth is currently served by two chapters of the national Alzheimer’s Association. The Greater Kentucky and Southern Indiana Chapter of the Alzheimer’s Association serve all but nine (9) counties in Northern Kentucky plus twelve (12) in Indiana. The Northern Kentucky Counties are part of the Greater Cincinnati Chapter.

## **Healthy Kentucky 2010**

Healthy Kentuckians 2010 is Kentucky's commitment to the national prevention initiative Healthy People 2010. Common overarching goals of these initiatives are to increase the quality and years of healthy life and eliminate health disparities. This document provides direction for individuals to change personal behaviors and for organizations and communities to support good health through health promotion policies. The following are current Healthy Kentucky objectives under the “Access to Quality Health Services: Clinical Preventive Services” section:

10.5 (Developmental) Increase the proportion of physicians, physician assistants, nurses and other clinicians who receive appropriate training to address important health disparities: disease prevention and health promotion, minority health, women’s health, *geriatrics*.

10.21. (Developmental) Increase the proportion of primary care providers who routinely evaluate, treat, and, if appropriate, refer their long-term care patients to subacute rehabilitative and other services to address:

- Physical mobility
- Urinary incontinence
- Polypharmacy
- Communicating and hearing disorders
- Depression
- *Dementia*
- Mental disorders, including alcoholism & substance abuse

### **Cabinet for Health and Family Services Plan**

Currently, the Cabinet for Health and Family Services Plan does not specifically address services for or persons with AD; however, the following performance indicators specified increases in training opportunities for adult protective service workers:

- #53.3.2.1 Increase adult protective services training opportunities for staff from 40% to 65%
- #53.3.2.2 Increase the number of counties having at least one worker trained in adult protective services policies and procedures from 85% to 98%

### **State Plan on Aging**

Kentucky's Department for Aging and Independent Living's State Plan on Aging (2005-2008), references AD in Section II, Planning and Service Delivery. Under the heading of Programs administered by the office of Alzheimer's includes Adult Day/Alzheimer's Disease Respite. This is a program of adult-day center services for persons aged 60 and who have physical disabilities or frail persons who are in need of supervision for part of a day, and center or in-home services for persons of any age with AD or other and related dementias.



## Existing Services

### Type, Cost, and Availability of Dementia Services

Kentucky currently has only one Alzheimer's Disease specific program. The Adult Day/Alzheimer's Disease Respite Program was created in statute (KRS 205.950) in 1992. This program provides services through adult-day center services for persons of any age with a diagnosis of Alzheimer's Disease. The program provides supervision for part of a day in a day care center or in home to allow caregivers to continue to work or take care of personal business or to simply rest. The chart below reflects current expenditures and utilization across Kentucky:

**Table 1.**  
**Expenditures Related to Respite Services provided In-Home and at Adult Day Care Centers.**

Service Venue	Number of Participants	Expenditure
In Home	89	\$150,189
Adult Day Care Centers (social)	592	\$1,236,286
<b>Total</b>	681	\$1,286,475

There are currently three individuals on the waiting list and eighteen who are considered underserved. This is a deceiving number as the service is limited by the availability of adult day care centers in the person's region and the availability of transportation to and from the center.

While there is only one dementia specific program that is funded with state general fund dollars, individuals and families use all of the existing Older American Act programs, state funded Homecare and appropriate mental health services.

In a report titled Nursing Home Data Compendium 2005 published by the United States Department of Health and Human Services, Centers for Medicare and Medicaid, it is estimated that 47% of Kentucky's 48,485 nursing home residents have moderate to severe Alzheimer's Disease while an additional 24% have mild or very mild Alzheimer's.

The following table outlines the average Medicare costs for beneficiaries age 65+ with AD and Co-morbidities, and comes from the statistical abstract of U.S. data on Alzheimer's Disease published by the Alzheimer's Association titled: Every 72 seconds someone in America develops Alzheimer's: Alzheimer's Disease Facts and Figures 2007

The information provided in Table 2 demonstrates that Alzheimer's is not a stand-alone disease but resides in the individual with other major co-morbid chronic disease. Additionally, the data depicts a drastic increase in cost for facility placement of individuals with a chronic disease and Alzheimer's. While there are no comparable data for Medicaid expenditures, it is a realistic expectation that the same cost assumptions can be made. The Kentucky Department for Aging and Independent Living does not require diagnostic data to be reported. Thus there is no conclusive information on the number of individuals who are being served with Alzheimer's in either the state general funded Homecare program or the Older Americans Act programs.

**Table 2.**  
**Average Medicare Costs for Beneficiaries Age 65+ with Alzheimer's Disease and Related Dementias Who Had Specified Coexisting Medical Conditions, 2000**

<b>Population</b>	<b>Cost Per Person</b>	<b>Hospital Cost</b>	<b>State Nursing Facility Cost</b>	<b>Home Health Cost</b>
<b>All beneficiaries</b>	<b>\$5,329</b>	<b>\$2,640</b>	<b>\$383</b>	<b>\$238</b>
All beneficiaries with no AD/D	4,454	2,204	210	190
<b>All with AD/D</b>	<b>13,207</b>	<b>7,074</b>	<b>2,144</b>	<b>728</b>
<b>With CHD</b>				
CHD and no AD/D	11,078	6,559	526	391
<b>CHD + AD/D</b>	<b>21,538</b>	<b>12,273</b>	<b>3,329</b>	<b>1,013</b>
<b>With Diabetes</b>				
Diabetes and no AD/D	8,011	4,207	420	455
<b>Diabetes+AD/D</b>	<b>19,994</b>	<b>10,943</b>	<b>3,021</b>	<b>1,265</b>
<b>With CHF</b>				
CHF and no AD/D	15,441	9,441	1,016	765
<b>CHF + AD/D</b>	<b>22,939</b>	<b>13,178</b>	<b>3,658</b>	<b>1,222</b>
<b>With COPD</b>				
COPD and no AD/D	12,450	7,580	744	463
<b>COPD + AD/D</b>	<b>23,693</b>	<b>13,980</b>	<b>3,643</b>	<b>992</b>

SNF = Medicare-covered skilled nursing facility  
 AD/D = Alzheimer's disease and related dementias  
 CHD = Coronary heart disease  
 CHF = Congestive heart failure  
 COPD = Chronic obstructive pulmonary disease, including emphysema

Care for individuals with AD and related dementias also occurs in mental health arenas. In a report from the Kentucky Department for Mental Health and Mental Retardation Services, there are 230 individuals with a diagnosis of Alzheimer's Disease being treated through the mental health centers in the 15 Community mental health districts. Current data from the 8 state mental health hospitals and nursing facilities and intermediate care facilities for those with mental retardation shows an additional 105 individuals who have AD or related dementias being treated in those facilities.

The entire issue of caregiver support and the cost to both caregivers and the business community has been well documented through large studies from Metropolitan Life Insurance Company and the Alzheimer's Association. In the Alzheimer's Association publication Every 72 seconds someone in America develops Alzheimer's: Alzheimer's Disease Facts and Figures 2007 the "Direct and indirect costs of Alzheimer's and other dementias, including Medicare and Medicaid costs and the indirect cost to business of employees who are caregivers of persons with Alzheimer's, amount to more than \$148 billion annually.

- State and federal Medicaid spending for nursing home care for people with Alzheimer's and other dementias was estimated at \$21 billion in 2005. It is projected to increase to \$24 billion in 2010 and \$27 billion in 2015.
- Costs to business for employees who are caregivers of people with Alzheimer's and other dementias amount to \$36.5 billion. These costs result from lost productivity, missed work and costs to replace workers who leave their jobs to meet the demands of caregiving.

Based on data from THE METLIFE STUDY OF EMPLOYER COSTS FOR WORKING CAREGIVERS *Family Caregiving in the U.S.: Findings from a National Survey*, loss of productivity due to lost work time and inattention to duties contribute to a total cost to U.S. business, of \$11.4 billion per year for caregivers of aging individuals of all diagnoses. The cost offset of care provided in the home providing services to individuals with Alzheimer's Disease and related dementias is estimated to be \$84 billion.

### **Capacity of public safety and law enforcement to respond to persons with Alzheimer's Disease**

One of the most alarming, potentially life threatening, and common behaviors which accompanies Alzheimer's disease is wandering. In the early stages of the disease, people can get lost along a familiar route because they can no longer recognize landmarks or remember the names of streets. In later stages, wandering often takes the form of aimless, frequent ambulation without any seeming goal. At any stage the activity can and often does result in individuals wandering away from their caregivers; placing them at risk of becoming lost, injured, or exposed to the elements. One cannot predict when the wandering behavior will occur, becoming a public safety issue that will also involve law enforcement.

Kentucky's Department of Criminal Justice Training (DOCJT) is a nationally recognized agency that provides state-of-the-art training to law enforcement officers in Kentucky. The DOCJT provides entry-level and professional-development training for approximately 12,000 students each year, including city, county, airport and state university police officers, sheriffs, deputy

sheriffs, coroners and law enforcement telecommunicators. DOCJT also offers training to officers from other state and federal agencies.

Nationally, there are nearly 125,000 cases a year called into local law enforcement agencies reporting a lost victim of Alzheimer's disease who has wandered away from home or a health care facility. Sometimes, these episodes of wandering end in tragedy for the person with Alzheimer's and their loved ones. In response to this growing concern, several local agencies and a health care provider have teamed up to create a program that will educate emergency personnel and caregivers on how to search and rescue someone with Alzheimer's disease and how to help make caregivers homes and health care facilities safer to prevent wandering in the first place.

Wellington Parc, Green River ADD, Green River AAA, and the Daviess County Emergency Management Agency have teamed up to develop the Alzheimer's Wandering and Rescue Education (AWARE) program. This is a free seminar, open to the public, and offered to police officers, emergency rescue personnel, family caregivers and professional caregivers. The training covers topics such as the etiology of Alzheimer's disease, communication, overall safety, behavioral problems, Alzheimer's sundowning, effective search and rescue techniques, and a home safety checklist.

#### **Availability of home and community based resources and respite care**

Kentucky is quickly moving toward improving options for community and home based care for individuals who are Medicaid eligible through the Consumer Directed Option for the Home and Community Based Waiver and the Money Follows the Person Grant. This is not true for those who are not eligible for Medicaid services either functionally or financially. Community based funding for the federal Older Americans Act programs have been essentially flat funded for ten years. Although Kentucky general funds have been increased in the last biennial budget, funds still fall short of meeting the need for services. Table 3 depicts stages of the disease as identified by Dr. Barry Resberg at New York University and the availability of and gaps in services specific to Kentucky for each stage. Table 4 provides a summary of services at each stage and potential payor sources for the required level of service.

**Table 3. Stages of Alzheimer’s Disease, Current Medicaid and Non Medicaid**

<b>Stage</b>	<b>Symptoms</b>	<b>Needs</b>	<b>Current Services in Kentucky</b>	<b>Gaps in Service in Kentucky</b>
<b>1</b> <b>Early</b>	No impairment (normal function)	Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.	None Alzheimer’s Association for education and referral	None
<b>1</b> <b>Early</b>	No impairment (normal function)	Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.	None	None
<b>2</b> <b>Early</b>	Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease)	Individuals may feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.	<ul style="list-style-type: none"> <li>• Medical Evaluation</li> <li>• Alzheimer’s Association for education and referral</li> </ul>	<ul style="list-style-type: none"> <li>• Only 10 geriatric Psychiatrists in the state.</li> <li>• Rural areas in both eastern and western Kentucky are underserved by specialty medical services.</li> <li>• Few experts in Elder law outside of major cities.</li> </ul>
<b>2</b>	Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease)	Individuals may feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or	<ul style="list-style-type: none"> <li>• Medical Evaluation</li> <li>• Alzheimer’s Association for education</li> </ul>	<ul style="list-style-type: none"> <li>• Only 10 geriatric Psychiatrists in the state.</li> <li>• Rural areas in both eastern and western Kentucky are underserved by specialty medical services.</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Early</b>		apparent to friends, family or co-workers.		<ul style="list-style-type: none"> <li>• Few experts in Elder law outside of major cities.</li> </ul>
<b>3</b>	Mild cognitive decline <i>Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms</i>	<p>Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:</p> <ul style="list-style-type: none"> <li>• Word- or name-finding problems noticeable to family or close associates</li> <li>• Decreased ability to remember names when introduced to new people</li> <li>• Performance issues in social or work settings noticeable to family, friends or co-workers</li> <li>• Reading a passage and retaining little material</li> <li>• Losing or misplacing a valuable object</li> <li>• Decline in ability to plan or organize</li> </ul>	<ul style="list-style-type: none"> <li>• Medical Evaluation-Diagnosis possible</li> <li>• Early Stage Support groups</li> <li>• Medication if indicated</li> <li>• Adult day care</li> <li>• Alzheimer's Association for education and referral</li> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• As above</li> <li>• Support groups not available in all counties</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Early</b>				
<b>3</b>	Mild cognitive decline <i>Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms</i>	<p>Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:</p> <ul style="list-style-type: none"> <li>• Word- or name-finding problems noticeable to family or close associates</li> <li>• Decreased ability to remember names when introduced to new people</li> <li>• Performance issues in social or work settings noticeable to family, friends or co-workers</li> <li>• Reading a passage and retaining little material</li> <li>• Losing or misplacing a valuable object</li> <li>• Decline in ability to plan or organize</li> </ul>	<ul style="list-style-type: none"> <li>• Medical Evaluation-Diagnosis possible</li> <li>• Early Stage Support groups</li> <li>• Medication if indicated</li> <li>• Adult day care</li> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• As above</li> <li>• Support groups not available in all counties</li> </ul>
<b>Early</b>				
<b>4</b>	Moderate cognitive decline (Mild or early-stage)	At this stage, a careful medical interview detects clear-cut deficiencies in the	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient funding for Homecare (1,835 Waiting list of 8300)</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Early</b>	Alzheimer's disease)	<p>following areas:</p> <ul style="list-style-type: none"> <li>• Decreased knowledge of recent occasions or current events</li> <li>• Impaired ability to perform challenging mental arithmetic-for example, to count backward from 75 by 7s</li> <li>• Decreased capacity to perform complex tasks, such as planning dinner for guests, paying bills and managing finances</li> <li>• Reduced memory of personal history</li> </ul> <p>The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations</p>	<ul style="list-style-type: none"> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Education and Support Groups</li> <li>• Assisted Living</li> <li>• Nursing Facility</li> <li>• Family Care Home</li> <li>• Adult day care</li> <li>• Alzheimer’s Association</li> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient funding for Meals on Wheels (waiting list of 1,079)</li> <li>• Insufficient Funding for respite (waiting list of 113)</li> <li>• Need additional training for paid in home caregivers</li> <li>• Regulation of private respite companies operating in Kentucky</li> </ul>
<b>4</b>	Moderate cognitive decline (Mild or early-stage Alzheimer's disease)	<p>At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:</p> <ul style="list-style-type: none"> <li>• Decreased knowledge of recent occasions or current events</li> <li>• Impaired ability to perform challenging mental arithmetic-for example, to count backward from</li> </ul>	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Education and Support Groups</li> <li>• Assisted Living</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>• Insufficient State funding for Meals on Wheels(1,079 on waiting list)</li> <li>• Insufficient State Funding for respite</li> </ul>



Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
Early		<p>75 by 7s</p> <ul style="list-style-type: none"> <li>Decreased capacity to perform complex tasks, such as planning dinner for guests, paying bills and managing finances</li> <li>Reduced memory of personal history</li> </ul> <p>The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations</p>	<ul style="list-style-type: none"> <li>Nursing Facility</li> <li>Family Care Home</li> <li>Adult day care</li> <li>Medic Alert Safe Return</li> </ul>	<p>(113 on waiting list)</p> <ul style="list-style-type: none"> <li>Need additional training for paid in home caregivers</li> <li>Regulation of private respite companies operating in Kentucky</li> </ul>
5	Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease)	<p>Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:</p> <ul style="list-style-type: none"> <li>Be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated</li> <li>Become confused about where they are or about the date, day of the week or season</li> <li>Have trouble with less challenging</li> </ul>	<ul style="list-style-type: none"> <li>Medical Assistance</li> <li>Medications</li> <li>Respite for family</li> <li>Homecare and Meals on Wheels</li> <li>Financial Assistance</li> <li>Home Health</li> <li>Private Caregivers</li> <li>Education and Support Groups</li> <li>Assisted Living</li> <li>Nursing Facility</li> <li>Family Care Home</li> <li>Adult day care</li> <li>Alzheimer's Association</li> <li>Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>Insufficient State funding for Meals on Wheels(1,079 on waiting list)</li> <li>Insufficient State Funding for respite (113 on waiting list)</li> <li>Need additional training for paid in home caregivers</li> <li>Regulation of private respite companies</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Mid</b>		<p>mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s</p> <ul style="list-style-type: none"> <li>• Need help choosing proper clothing for the season or the occasion Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children</li> <li>• Usually require no assistance with eating or using the toilet</li> </ul>		operating in Kentucky
<b>5</b>	Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease)	<p>Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:</p> <ul style="list-style-type: none"> <li>• Be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated</li> <li>• Become confused about where they are or about the date, day of the week</li> </ul>	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Education and Support Groups</li> <li>• Assisted Living</li> <li>• Nursing Facility</li> <li>• Family Care Home</li> <li>• Adult day care</li> <li>• Alzheimer's Association</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>• Insufficient State funding for Meals on Wheels(1,079 on waiting list)</li> <li>• Insufficient State Funding for respite (113 on waiting list)</li> <li>• Need additional training for paid in home caregivers</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Mid</b>		<p>or season</p> <ul style="list-style-type: none"> <li>• Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s</li> <li>• Need help choosing proper clothing for the season or the occasion</li> <li>• Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children</li> </ul> <p>Usually require no assistance with eating or using the toilet</p>	<ul style="list-style-type: none"> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• Regulation of private respite companies operating in Kentucky</li> </ul>
<b>6</b>	<p>Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease)</p>	<p>Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:</p> <ul style="list-style-type: none"> <li>• Lose most awareness of recent experiences and events as well as of their surroundings</li> <li>• Recollect their personal history imperfectly, although they generally recall their own name</li> </ul>	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Education and Support Groups</li> <li>• Assisted Living</li> <li>• Nursing Facility</li> <li>• Family Care Home</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>• Insufficient State funding for Meals on Wheels(1,079 on waiting list)</li> <li>• Insufficient State Funding for respite (113 on waiting list)</li> <li>• Need additional</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
		<ul style="list-style-type: none"> <li>• Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces</li> <li>Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet</li> <li>• Experience disruption of their normal sleep/waking cycle</li> <li>• Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)</li> <li>• Have increasing episodes of urinary or fecal incontinence</li> <li>• Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding</li> </ul> <p>Tend to wander and become lost</p>	<ul style="list-style-type: none"> <li>• Alzheimer’s Association</li> <li>• Adult Day</li> <li>• Medic Alert Safe Return</li> </ul>	<p>training for paid in home caregivers</p> <ul style="list-style-type: none"> <li>• Regulation of private respite companies operating in Kentucky</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Mid</b>				
<b>6</b>	Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease)	<p>Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:</p> <ul style="list-style-type: none"> <li>• Lose most awareness of recent experiences and events as well as of their surroundings</li> <li>• Recollect their personal history imperfectly, although they generally recall their own name</li> <li>• Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces</li> <li>• Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet</li> <li>• Experience disruption of their normal sleep/waking cycle</li> <li>• Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)</li> <li>• Have increasing episodes of</li> </ul>	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Education and Support Groups</li> <li>• Assisted Living</li> <li>• Nursing Facility</li> <li>• Family Care Home</li> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>• Insufficient State funding for Meals on Wheels(1,079 on waiting list)</li> <li>• Insufficient State Funding for respite (113 on waiting list)</li> <li>• Need additional training for paid in home caregivers</li> <li>• Regulation of private respite companies operating in Kentucky</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
<b>Mid</b>		urinary or fecal incontinence <ul style="list-style-type: none"> <li>• Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding</li> </ul> Tend to wander and become lost		
7	Very severe cognitive decline (Severe or late-stage Alzheimer's disease)	This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement. <ul style="list-style-type: none"> <li>• Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered</li> <li>• Individuals need help with eating and toileting and there is general incontinence of urine</li> </ul> Individuals lose the ability to walk	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Alzheimer's Association</li> <li>• Education and Support Groups</li> <li>• Nursing Facility</li> <li>• Hospice</li> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>• Insufficient State funding for Meals on Wheels(2,079 on waiting list)</li> <li>• Insufficient State Funding for respite (113 on waiting list)</li> <li>• Need additional training for paid in home caregivers</li> <li>• Regulation of private</li> </ul>

Stage	Symptoms	Needs	Current Services in Kentucky	Gaps in Service in Kentucky
Late		without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.		<ul style="list-style-type: none"> <li>• respite companies operating in Kentucky</li> <li>• Expanded Hospice benefit</li> </ul>
7  Late	Very severe cognitive decline (Severe or late-stage Alzheimer's disease)	<p>This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement.</p> <ul style="list-style-type: none"> <li>• Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered</li> <li>• Individuals need help with eating and toileting and there is general incontinence of urine</li> </ul> <p>Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.</p>	<ul style="list-style-type: none"> <li>• Medical Assistance</li> <li>• Medications</li> <li>• Respite for family</li> <li>• Homecare and Meals on Wheels</li> <li>• Financial Assistance</li> <li>• Home Health</li> <li>• Private Caregivers</li> <li>• Education and Support Groups</li> <li>• Nursing Facility</li> <li>• Hospice</li> <li>• Medic Alert Safe Return</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient State funding for Homecare (Total of 3,872 on waiting list)</li> <li>• Insufficient State funding for Meals on Wheels(1,079 on waiting list)</li> <li>• Insufficient State Funding for respite (113 on waiting list)</li> <li>• Need additional training for paid in home caregivers</li> <li>• Regulation of private respite companies operating in Kentucky</li> <li>• Expanded Hospice benefit</li> </ul>

**Table 4. Stages of Alzheimer’s Disease and Service Payor Sources**

<b>Stage</b>	<b>Symptoms</b>	<b>Current Services</b>	<b>Providers in Kentucky</b>	<b>Payor Source in Kentucky</b>
<b>1</b> <b>Early</b>	<b>No impairment (normal function)</b>	N/A	N/A	N/A
<b>2</b>  <b>Early</b>	<b>Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer’s disease)</b>	Medical Evaluation	Physicians	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> </ul>
		Caregiver Education & Training	Alzheimer’s Association	<ul style="list-style-type: none"> <li>▪ Donations &amp; Fees</li> </ul>
			Home Health	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Private Insurance</li> </ul>
			National Family Caregiver Support Program	<ul style="list-style-type: none"> <li>▪ Administration on Aging with Local Match</li> </ul>
<b>3</b>	<b>Mild cognitive decline</b> <b>Early-stage Alzheimer’s can be diagnosed in some, but not all, individuals with these symptoms</b>	Medical Evaluation-Diagnosis Possible	Private Physicians	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> </ul>
		Early Stage Support Groups	Alzheimer’s Association	<ul style="list-style-type: none"> <li>▪ Donations &amp; Fees</li> </ul>



Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
Early		Medication if indicated	Physician Order	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> </ul>
		Adult Day Care	Adult Day Care Social Model	<ul style="list-style-type: none"> <li>▪ Private Insurance</li> <li>▪ Older Americans Act</li> <li>▪ State General Funds</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
			Adult Day Health Care	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
4	Moderate cognitive decline (Mild or early-stage Alzheimer's disease)	Medical Assistance	Physicians	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Medications	Pharmacies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
	Moderate cognitive decline (Mild or early-stage Alzheimer's disease)	Respite for Family	Private Caregivers Home Health Agencies Medicaid Older Americans Act program Homecare Adult Day Care Adult Day Health Care	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> <li>▪ Area Agencies on Aging</li> <li>▪ National Family Caregiver Support Program</li> <li>▪ Older Americans Act</li> <li>▪ State General Funds</li> </ul>
		Homecare and Meals on Wheels	Area Agencies on Aging & Subcontractors	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Older Americans Act</li> </ul>
		Financial Assistance	Attorneys Bankers Fee for Service Counselors	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Home Health	Licensed Home Health Agencies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Private Caregivers	Independent Providers	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
Early	Moderate cognitive decline (Mild or early-stage Alzheimer's disease)	Education & Support Groups	Alzheimer's Association	<ul style="list-style-type: none"> <li>▪ Donations &amp; Fees</li> </ul>
		Assisted Living	Certified Assisted Living Facilities	<ul style="list-style-type: none"> <li>▪ Limited rental assistance</li> <li>▪ Private Pay</li> </ul>
		Nursing Facility	Licensed Facilities	<ul style="list-style-type: none"> <li>▪ Limited Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Family Care Home	Licensed Homes	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Adult Day Care	Certified Social Model	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Private Pay</li> </ul>
			Licensed Health Model	<ul style="list-style-type: none"> <li>▪ Medicaid (Health model)</li> <li>▪ State General Funds</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
5	Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease)	Medical Assistance	Physicians	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Medications	Pharmacies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Respite for Family	Private Caregivers Home Health Agencies Medicaid Older Americans Act Programs Homecare Adult Day Care Adult Day Health Care	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> <li>▪ Area Agencies on Aging</li> <li>▪ National Family Caregiver Support Program</li> <li>▪ Older Americans Act</li> <li>▪ State General Funds</li> </ul>
	Moderately severe cognitive decline (Moderate or mid-	Homecare and Meals on Wheels	Area Agencies on Aging & Subcontractors	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Older Americans Act</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky	
<b>Mid</b>	<b>stage Alzheimer's disease)</b>	Financial Assistance	Attorneys Bankers Fee for Service Counselors	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>	
		Home Health	Licensed Home Health Agencies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>	
		Private Caregivers	Independent Providers	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>	
		Education & Support Groups	Alzheimer's Association	<ul style="list-style-type: none"> <li>▪ Donations &amp; Fees</li> </ul>	
		Assisted Living	Certified Assisted Living Facilities	<ul style="list-style-type: none"> <li>▪ Limited rental assistance</li> <li>▪ Private Pay</li> </ul>	
		<b>Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease)</b>	Nursing Facility	Licensed Facilities	<ul style="list-style-type: none"> <li>▪ Limited Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Family Care Home	Licensed Homes	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>	

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
		Adult Day Care	Certified Social Model	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Private Pay</li> </ul>
			Licensed Health Model	<ul style="list-style-type: none"> <li>▪ Medicaid (Health Model)</li> <li>▪ State General Funds</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
6	<b>Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease)</b>	Medical Assistance	Physicians	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Medications	Pharmacies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
	Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease)	Respite for Family	Private Caregivers Home Health Agencies Medicaid Older Americans Act Programs Homecare Adult Day Care Adult Day Health Care	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> <li>▪ Area Agencies on Aging</li> <li>▪ National Family Caregiver Support Program</li> <li>▪ Older Americans Act</li> <li>▪ State General Funds</li> </ul>
		Homecare and Meals on Wheels	Area Agencies on Aging & Subcontractors	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Older Americans Act</li> </ul>
		Financial Assistance	Attorneys Bankers Fee for Service Counselors	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Home Health	Licensed Home Health Agencies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Private Caregivers	Independent Providers	<ul style="list-style-type: none"> <li>▪ Private pay</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
<b>Mid</b>		Education & Support Groups	Alzheimer's Association	<ul style="list-style-type: none"> <li>▪ Donations &amp; Fees</li> </ul>
		Assisted Living	Certified Assisted Living Facilities	<ul style="list-style-type: none"> <li>▪ Limited Rental Assistance</li> <li>▪ Private Pay</li> </ul>
		Nursing Facility	Licensed Facilities	<ul style="list-style-type: none"> <li>▪ Limited Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Family Care Home	Licensed Homes	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Adult Day Care	Certified Social Model	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Private Pay</li> </ul>
			Licensed Health Model	<ul style="list-style-type: none"> <li>▪ Medicaid (Health Model)</li> <li>▪ State General Funds</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>



Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
7	Very severe cognitive decline (Severe or late-stage Alzheimer's disease)	Medical Assistance	Physicians	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Medications	Pharmacies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Respite for Family	Private Caregivers Home Health Agencies Medicaid Older Americans Act Programs Homecare Adult Day Care Adult Day Health Care	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> <li>▪ Area Agencies on Aging</li> <li>▪ National Family Caregiver Support Program</li> <li>▪ Older Americans Act</li> <li>▪ State General Funds</li> </ul>
		Homecare & Meals on Wheels	Area Agencies on Aging & Subcontractors	<ul style="list-style-type: none"> <li>▪ State General Funds</li> <li>▪ Older Americans Act</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
<b>Late</b>	<b>Very severe cognitive decline (Severe or late-stage Alzheimer's disease)</b>	Financial Assistance	Attorneys Bankers Fee for Service Counselors	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Home Health	Licensed Home Health Agencies	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Private Caregivers	Independent Providers	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Education & Support Groups	Alzheimer's Association	<ul style="list-style-type: none"> <li>▪ Donations &amp; Fees</li> </ul>
		Assisted Living	Certified Assisted Living Facilities	<ul style="list-style-type: none"> <li>▪ Limited Rental Assistance</li> <li>▪ Private Pay</li> </ul>
		Nursing Facility	Licensed Facilities	<ul style="list-style-type: none"> <li>▪ Limited Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> </ul>
		Family Care Home	Licensed Homes	<ul style="list-style-type: none"> <li>▪ Private Pay</li> <li>▪ State General Funds</li> </ul>

Stage	Symptoms	Current Services	Providers in Kentucky	Payor Source in Kentucky
			Certified Social Model	<ul style="list-style-type: none"> <li>▪ Private Pay</li> </ul>
		Adult Day Care	Licensed Health Model	<ul style="list-style-type: none"> <li>▪ Medicaid (Health Model)</li> <li>▪ State General Funds</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>
		Hospice	Licensed Hospice	<ul style="list-style-type: none"> <li>▪ Medicare</li> <li>▪ Medicaid</li> <li>▪ Private Insurance</li> <li>▪ Private Pay</li> </ul>

## **Services and Gaps in Services Specific to Kentucky**

### **Inventory of long term care special dementia units**

Service approaches provided through special care units for dementia in long-term care facilities potentially offer better care for residents than nursing homes without such specially structured programs. Because residents with dementia can be disruptive to other residents, difficult to manage and times, and challenging to health care professionals charged with their care, a structured approach to care targets specific stages and behaviors that are common with the disease. Currently, there are more than 36 long term care dementia units in Kentucky.

### **Adequacy and appropriateness of geriatric psychiatry units for persons with behavior disorders associated with AD**

All psychiatry beds are required to be licensed in Kentucky and the licensing categories include, child, adolescent, adult, or geriatric. According to the Office of Inspector General, there are currently twenty four licensed geriatric psychiatry beds in the Commonwealth; however, the utilization of psychiatric beds by the elderly may be underestimated because they may also be served under the adult licensure. According to information received from the 2006 Annual Kentucky Hospital Utilization and Services Report, there are approximately 2,855 licensed psychiatric inpatient hospital beds in Kentucky for adults 18 years of age and over. Of the 2,855, the total is unknown for the number of beds that are in service (actively used – still funded). Additionally, there are 3 outpatient programs for older adults.

### **Assisted living residential options for persons with dementia**

There are currently 100 certified assisted living facilities. Of those 100 there are twelve (12), which have special dementia units with locked doors. Regulations limit the use of Assisted Living to the early or mid stages of the disease. In Kentucky, medications may not be administered to the individuals nor can any other medical care be given. As seen in Table 2 individuals with Alzheimer's often have serious chronic co-morbid disease which limits the use of Assisted Living. At the present time, there are 2 assisted living units that accept HUD rental subsidy; however, each housing tower is located side by side in Louisville. The other ninety nine (99) facilities require lease agreements and cash payment unless the individual has some form of long term care insurance, which covers that level of care.

## **Research**

Competitive funding for AD research represents a major challenge for researchers. Federal programs sponsored by the National Institutes of Health (NIH) currently fund only the top 8% of grants submitted. These funding awards are not evenly distributed across states. Researchers in Kentucky must compete independently for funds with researchers throughout the United States. Unlike states such as California and Florida, Kentucky does not have any targeted funds for AD research for Kentucky's unique population. Private funding sources are also available to researchers but such funding opportunities are also extremely competitive.

Although the Universities of Kentucky and Louisville are actively participating in AD research, state supported funding for this public health crisis has been insignificant. On the other hand, under the leadership of Commissioner Deborah Anderson through the newly formed Department for Aging and Independent Living, staff have recently become more aggressive in partnering with various institutions to compete for federal grants and secure funding. Following is a brief summary of current research initiatives, education, outreach, and funding sources at the national, state, and community level. Complex medical studies will not be summarized, please contact the various Departments for more medical detail.

### **National Resources**

In 1974, Congress created the National Institute on Aging (NIA) with a mission to gain further insight into normal aging. The NIA, part of the NIH, is the lead Federal agency for AD research. Currently, the NIA funds 29 Alzheimer's Disease Centers (ADCs) at major medical institutions across the United States. Through these centers, scientists are testing a number of drugs to see if they prevent AD, slow the disease, or help reduce symptoms. Researchers undertake clinical trials to learn whether treatments that appear promising in observational and animal studies actually are safe and effective in people. Although each center has its own unique areas of emphasis, common goals include the enhancement of research by providing a network for sharing new ideas. Research is also supported by the National Alzheimer's Coordinating Center through the coordination of data collection and fostering collaborative research among the centers. Additionally, the National Cell Repository for Alzheimer's Disease maintains a database of family histories and medical records and provides genetic researchers with cell lines and/or DNA samples.

The National Institute on Aging (NIA), part of the National Institutes of Health (NIH), is the lead Federal agency for AD research. Since the formation of NIA by Congress in 1974 supported scientists are testing a number of drugs to see if they prevent AD, slow the disease, or help reduce symptoms. Researchers undertake clinical trials to learn whether treatments that appear promising in observational and animal studies actually are safe and effective in people.

Still, community level information and support was lacking. In response, a small group of family Alzheimer caregivers founded the Alzheimer's Association in 1980. Currently, the Association consists of 78 chapters nationwide and is the leading source of support, education, and advocacy for those affected by AD and related dementias. The Alzheimer's Association is the largest private non-profit funding source of research in the United States.

### **State Resources**

Despite the competitiveness of securing federally funded grants, both the University of Kentucky and the University of Louisville have had many successes across various areas of study. Each University also has Centers designated for Alzheimer's and related dementias research. For the sake of brevity, the following summaries regarding research at the Universities of Kentucky and Louisville are brief and limited in scope. Please contact the various University Departments for more detailed information.

***University of Kentucky.*** Currently, there is one Alzheimer's Disease Center (ADC) funded by NIA in Kentucky, University of Kentucky's Sanders-Brown Center on Aging. Research at the UK ADC is focused on developing an understanding of age-related diseases including AD, stroke, and prion diseases. Prion diseases belong to a group of progressive conditions that affect the nervous system in humans and animals. In people, prion diseases impair brain function, causing memory changes, personality changes, dementia, and problems with movement that worsen over time. Familial prion diseases of humans include classic Creutzfeldt-Jakob disease, Gerstmann-Sträussler-Scheinker syndrome, and fatal insomnia. Animal disease versions include chronic wasting disease in deer and elk and "mad cow" disease in cattle.

Cutting edge research at the UK Sanders-Brown Center on Aging ranges from basic laboratory science to clinical trials. The overall goal of Center research is to understand dementing disorders so that they can be successfully treated and prevented. This ADC also supports 10 other NIH and Alzheimer's Association grants at the University of Kentucky. Governor Martha Layne Collins along with the 1986 Kentucky General Assembly designated the Center as a Commonwealth Center on Excellence in Aging.

Between the years of 1989 and 1995 researchers at UK produced over 450 professional research publications and obtained 34 federal and industry research grant awards totaling \$8.9 million. The subsequent 5-year interval (1995-2000) included continued research productivity resulting in over 390 publications and 54 grants totaling \$40.5 million in new and ongoing research support for AD. Research at UK's ADC continued to flourish from year 2000 through 2005, with 340 research publications and continued grant support of \$44 million. The Center also partners with other national entities (federally and industry funded), the Alzheimer's Disease Neuroimaging Initiative and the Alzheimer's Disease Cooperative Study Group. An educational component of the program provides support to families, caregivers, health professionals, and persons with AD. Funding for this educational program is currently limited to a small

independently secured grant from the national Alzheimer's Association, which will expire in 2009. Since 1989 UK's ADC Sander's-Brown Center for Aging has also been studying normal, healthy brain aging in research participants from Fayette and surrounding counties in central Kentucky (BRAiNS program).

***University of Louisville.*** Research specific to AD at the University of Louisville crosses the Departments of Biochemistry and Molecular biology, Pathology and Laboratory Medicine, Family and Geriatric Medicine, as well as the Gheens Center on Aging, and the University Research Foundation.

Since 1984 the Department of Family and Geriatric Medicine has sponsored an interdisciplinary Geriatric Evaluation and Treatment Unit focusing on assessment, diagnosis, and treatment of AD patients and their families. Students and faculty from other Departments such as Psychological and Brain Sciences and Kent School of Social Work derive research subjects and projects from this program. Additional activities of the Department focus on estimating the prevalence of cognitive impairment in primary care, identifying provider attitudes that create challenges to diagnosing AD among primary care patients, and the linkage between screening with clock drawing and identification of middle aged and older adults with AD.

In 2000, the Gheens Center for Aging and Age-Related Diseases was established in U of L's School of Medicine with a \$2.5 million gift from the Gheens Foundation, a Louisville-based organization supporting charitable and educational endeavors. Research priorities at the Gheens Center on Aging focus on the role of genetic mechanisms in the aging process, an effort that could lead to ways of slowing or stopping adult-onset diabetes, some forms of cardiovascular disease such as stroke, and neurodegenerative diseases such as Parkinson's and Alzheimer's. Finally, the University Research Foundation, Inc. for Alzheimer's disease research received a three-year grant (\$240,000) in 2004 from the Alzheimer's Association to explore AD connections in cultured neurons.

***State Agency Supports and Studies Specific to Kentuckians.*** In 1989, the State Legislature designated \$244,000 to support three AD research positions within UK's Sanders-Brown Center on Aging. The State commitment stimulated additional research through the ADC resulting in clinical investigations into possible AD therapies as well as basic research into mechanisms involved in the development of AD.

More recently, \$100,000 of state general funds was budgeted to cross over fiscal years 2007 and 2008, to explore the effectiveness of dementia training in selected long-term care facilities. Furthermore, during the past year, DAIL secured a total of approximately \$1.2 million in research dollars to explore nursing home diversion, consumer directed options pilot focusing on goods and services, quality dementia care, legal services, and a state profile assessment. Kentucky also proposed to administer and evaluate practical applications of an evidence-based practice, the Savvy Caregiver Program, a curriculum designed to decrease caregiver burden for those who care for individuals with

Alzheimer's disease or related dementia in rural areas; however, the funding for this project was not awarded.

It should be noted that Kentucky's Quality Dementia Care Project includes an evaluation of the "Best Friends Approach to Dementia Care" in an Adult Day Care Center in a rural impoverished area and one in a predominantly African American community in an urban area. Although the Best Friends model is widely used by other states as well as internationally, until now, the anecdotal benefits of this program have not been empirically tested.

Although Kentucky does not designate funds for Alzheimer's Disease research to be applied toward studies including Kentucky's unique population, both UK and U of L have successfully secured funding and recruited Kentucky residents for studies focusing on changes in brain functioning as it relates to aging. Since 1989 UK's ADC Sanders-Brown Center for Aging has been studying normal, healthy brain aging in research participants from Fayette and surrounding counties in central Kentucky. The group, self-named as the "Biological Resilient Adults in Neurological Studies" cohort (BRAiNS), has aided in unlocking the mysteries of memory and thinking changes associated with normal healthy brain aging. Participants receive yearly physical and neurological examinations, tests of memory and thinking, and agree to donate their brain tissue at death. Research activities at the U of L include neurodegenerative autopsy services for the Louisville region to determine the pathologic diagnosis of clinical dementia. The information gained from the autopsy is used for the confirmation of clinical diagnosis for the family and the advancement of education for medical investigators for research studies focusing on neurodegeneration.

### **Evidenced Based Practices**

An evidence-based practice is a practice that has been or is being evaluated resulting in some quantitative and qualitative data that supports general positive public health outcomes. The research or evaluation of the practice has also been subject to expert or peer review resulting in a significant level of evidence of effectiveness as described in public health research literature. Due to the potential detrimental personal, social, and health impacts of caring for an individual with AD, most evidence-based training curriculums are targeted toward the family caregiver. Some studies have demonstrated that caregiver training delays nursing home placement of the individual with AD by as many as 557 days, or approximately 1.5 years.

The Administration on Aging currently lists the following 7 curriculums as evidence-based practices: 1) Managing Difficult Behaviors: A Standardized Intervention to Help Family Caregivers (STAR-C), 2) Making Sense of Memory Loss, 3) The New York University Counseling and Support Intervention for Caregivers, 4) Reducing Disability in Alzheimer's Disease (RDAD), 5) Resources for Enhancing Alzheimer's Caregiver Health I REACH I), 6) REACH II, and 7) Savvy Caregiver. A brief summary of each evidence-based practice is provided in Appendix C.



In summary, State support for AD research has not increased since the initial investment in 1989, leaving researchers at institutions like UK's Sanders-Brown Center on Aging to seek alternative means of support. While UK and U of L AD researchers have shown that they can successfully compete for extramural funding, current federal and private funding cutbacks will make the work of AD researchers even more difficult.

### **CHAPTER 3: IDENTIFIED ISSUES OR CHALLENGES AND CORRESPONDING RECOMMENDATIONS**

This chapter details the identified issues or challenges and corresponding recommendations designed to improve state role and infrastructure, programs and services, and research and evaluation. An estimated completion data follows each recommendation.

#### **State Role and Infrastructure**

**Identified Challenge:** Fragmented and under funded State system in long-term care

**SJR 6 Goal:** Build appropriate infrastructure to support the State role in long-term care, family caregiver support and assistance

Realizing the imminent problem of age related neurodegenerative diseases, the 2000 Kentucky legislature created by statute (KRS 194A.601) the Office of Alzheimer’s Disease and Related Disorders.

The Office was required to be included within the Cabinet for Health Services and was charged with overseeing information and resources related to policy and services affecting sixty thousand residents of Kentucky with dementia, and the caregivers and families of the residents.

The legislation called for the Office to have a Director; however, duties for the Office and the duties ascribed to it were absorbed into the Office of Aging Services by utilizing existing state staff.

The same Legislation created the Alzheimer’s Disease and Related Disorders Advisory Council. The Council was to provide recommendations to the Office, elect a chair, select the Office Director, establish goals and evaluate services and supports for those individuals and families dealing with this terminal disease. The membership of the Council was delineated in the statute to include representation from three agencies of state government, three from local health departments, one from the University of Kentucky Alzheimer’s Disease Research Center at Sanders-Brown Center on Aging, one each from the Chapters of the Alzheimer’s Association serving the Commonwealth with the remainder of the fifteen representing consumers, health care providers and the medical research community. All members are appointed by the Governor’s office.

While the intent of the legislation was certainly valid, the “Office within an Office” as well as the Council, struggled to be effective due to the lack of clear structure, status and an identified funding source.

During the next few years the state infrastructure was restructured many times. Cabinets were separated and then put together, Departments were combined and Divisions eliminated. Over time, the Office of Aging Services became a Department and then a Division and the “Office” of Alzheimer’s Disease and Related Disorders was diminished to a .10 FTE staff position that coordinated quarterly Council meetings.

Despite these efforts to improve the infrastructure and organizational structure for Kentucky’s health care system, one factor remained the same. The system remained fragmented. Each Department created their own activities and programs for long-term care including dementia related services and supports but there were no centralized decision making, policy or coordination. Usually, each Department was not aware of the activities of the other Departments.

The toll a fragmented service and support system takes on the individual and their family, friends in charge of their caregiving can be insurmountable. Currently, of the five million Americans with Alzheimer’s, approximately 70% live at home, receiving most of their care from family members. The challenge of providing assistance with basic activities of daily living and watching the deterioration of their loved one results in an onslaught of physical and emotional stress as well as a significant financial strain. Our current system fails to adequately address the needs of caregivers across the state. As of June 30, 2007 there were 45 caregivers on the waiting list for respite care services. This number may be somewhat misleading in that not all counties have an Adult Day respite program and only one region offers in-home respite care services. In addition, the current eligibility and service requirements often prohibit the ability to provide services to caregivers of individuals with early on-set dementia. Without adequate support systems, these individuals will most likely end up in an institutional setting at a cost estimated to be four times higher than patients treated in the community.<sup>1</sup>

While families absorb most of the costs for the care of an Alzheimer’s patient, the federal and state governments are attempting to assist caregivers. Congress made alterations to the Federal Internal Revenue Code that allows caregivers to receive tax credit. On a state level, the Kentucky General Assembly attempted to pass Household and Dependent Care Credit in 2007.

Because locating, understanding and accessing public programs and services can be difficult in the fragmented system, Kentucky recently created the Kentucky Resource Market to assist in streamlining information and referral services. The Kentucky Resource Market provides one-on-one assistance by phone. Through the system “one call does it all” in finding the most appropriate program and service for their needs.

However, family members and caregivers realize that just finding a needed resource or service isn’t enough. Significant issues can arise due to the lack of knowledge of the providers regarding Alzheimer’s and related dementias. Family members and caregivers lament most staff are trained to assist the elderly but not specifically to the Alzheimer related diseases. There are limited training opportunities on Alzheimer’s and related dementia diseases across the state. Reasons for the limitations include the lack of

approved training materials steeped in evidence based practices, inadequate requirements to obtain training on Alzheimer's and related dementias or other components of the long term care system and a lack of qualified staff to provide the training.

The fragmented system has also resulted in an inability to collect specific data on the disease or other components of long term care. Currently Kentucky does not have a statewide data system or a centralized portal to submit the data. Determining data for this report, such as the number of geriatric psychiatrists in the state, required numerous calls and resulted in varying answers depending on which entity was contacted.

Additionally, providers, consumers and family members expressed significant concerns about the extreme diversity in how state staff, whether adult protective services workers, state guardians or health department nurses, worked with individuals with Alzheimer's. The Council concluded there is a clear lack of understanding on Alzheimer's and Dementia, the progressive stages of the disease, available services and supports and various placement options. Training for staff on working with this population has been sporadic resulting in each Department and individual worker often "making it up as they go along", often with unfortunate results for the consumer and family.

The current array of institutional care options is rigidly sub-divided based on providers' service capabilities and state regulations rather than on the changing needs of individuals; this is particularly problematic for persons with dementia because of their reliance on environmental consistency and reduced capacity for processing change. In addition, behavioral issues often result in continuous placement changes.

The importance of early detection and treatment for Alzheimer's and related dementias cannot be overstated. The earlier the diagnosis the more likely symptoms will respond to treatment. Additionally, many conditions with dementia-like symptoms are reversible. Early identification and aggressive treatment of Alzheimer's and other related dementias offer the greatest opportunity to decrease cost and progression of the disease. Despite the potential to reduce costs and reduce the rate of disease progression, many insurance plans, including Medicaid, incorporate barriers to treatment and services for early on-set of Alzheimer's disease and related dementias.

In Kentucky, there have been numerous efforts through various agencies to ensure the health, safety and welfare of this vulnerable population. However, this population brings along a multitude of challenges, issues and concerns when it comes to emergency management, preparedness, response and recovery. These individuals pose one of the greatest challenges to communities, families, friends and first responders. Although elder abuse is often a silent crime, Kentucky is a mandatory reporting state (KRS 209.030)

According to the Elder Abuse in Kentucky 2006 Annual Report, in 2005, the overall National average for substantiated cases of elder abuse, neglect and exploitation involving adults remained steady at about 47%; however, Kentucky realized a substantiation rate of 30% in 2005, and 29% in 2006 (SFY). Over the past several years, the substantiation rate has increased due to improved training for staff, the proposed

addition of designated APS staff, an increase in public awareness campaigns, as well as, assistance from the Office of Attorney General's Office in developing a Prosecutor's Manual. According to the same report, a total of 9,387 adult protective services cases were reported for individuals 60+ in State Fiscal Year 2006 and a total of 6,548 reports were investigated. The investigations resulted in 1,585 substantiated reports with the caretaker found to have neglected an elderly person in 21% of the cases, and 16% of the elderly were exploited.

In December 2006, the Department for Aging and Independent Living (DAIL) was created in an attempt to better coordinate the aforementioned and fragmented activities. DAIL administers programs and services, establishes policy and coordinates activities for long- term care regardless of the age or disability. In addition, DAIL strives to provide programs and services to ensure individual dignity, self-respect, and independence on behalf of Kentucky's elders and people with disabilities and focuses on removing challenges to improving the quality of life for these vulnerable Kentucky citizens.

The creation of the Department along with the mandates contained within State Joint Resolution Six have assisted the staff and Council in clearly identifying the issues and needs for creating a strong infrastructure and clearly delineating the State role within that infrastructure. The Council recommends the following:

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### **RECOMMENDATION 3.1**

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*Revise KRS 194A.601 to make the Office a viable, fully funded and staffed entity within the Department for Aging and Independent Living working in conjunction with the Council.*

#### **Strategies:**

- 3.1.1. Recreate the "office" to become the Alzheimer's and Related Dementias Unit working in conjunction with the Council. (2008)
- 3.1.2. Obtain specific State general funding to hire a full time coordinator and 2 FTE program staff for the Alzheimer's and Related Dementias Diseases Unit. (2008)
- 3.1.3. Expand the role of the Unit to include policy, research and coordination of services. (2008)
- 3.1.4. Require the Unit to conduct the following activities: (2008)
  - Disseminate information on services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, academic community, primary family caregivers,

advocacy associations and general public.

- Enhance the DAIL website to include Alzheimer’s information and links.
- Establish a strategy to link and coordinate services and activities of State agencies, other service providers, advocacy groups and other entities throughout the State such as emergency personnel, police, universities and attorneys and other staff associated with the legal system.
- Coordinate and provide support for Council activities.

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**RECOMMENDATION 3.2**

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*Increase and improve support for family caregivers*

**Strategies:**

- 3.2.1. Request an increase in the Alzheimer’s Respite Services line item in the State budget. (2008)
- 3.2.2. Utilize the Council and stakeholder community to revise the current definition, eligibility and service requirements for the provision of respite. (2008)
- 3.2.3. Ensure a system of care coordinators and benefit counselors in each of the 15 ADD regions. (2010)
- 3.2.4. Develop incentives beyond tax incentives for caregivers (2010)
- 3.2.5. Support legislation for a caregiver tax credit for people who provide in-home care for dependent relatives who have little to no income, and have been diagnosed with Alzheimer’s Disease and related dementias. (2008)
- 3.2.6. Develop a demonstration to test the feasibility and cost-effectiveness of adult day care clients receiving services in other long term care settings traditionally considered “institutional” in order to expand access and accommodate anticipated growth in demand. (2009)

### **RECOMMENDATION 3.3**

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*Develop, implement and coordinate a Statewide data collection system.*

**Strategies:**

- 3.3.1. Require the Alzheimer's and Related Dementias Unit to develop, implement and coordinate a Statewide data collection system. (2009)
- 3.3.2. Collect data and monitor at a minimum the following data: (2010)
  - a. The prevalence of dementia related diseases across the Commonwealth
  - b. The prevalence of dementia related diseases by county
  - c. The prevalence of early on-set dementia related diseases across the Commonwealth
  - d. The prevalence of inpatient geriatric psychiatry beds
  - e. The availability of geriatric services and specialists
  - f. The availability of dementia related services and supports
  - g. The availability of assessment services for Alzheimer's and dementia
  - h. The number and location (county) of Kentuckians who are currently providing care in their home to a family member.

### **RECOMMENDATION 3.4**

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*Develop and implement training on Alzheimer's and Dementia Related Disorders for various stakeholders.*

**Strategies:**

- 3.4.1 Identify specific training resources for targeted audiences across the State. (2009)
- 3.4.2 Develop relationships with police and community partners to develop and implement training (such as, but not excluding, bankers, attorneys, police, emergency personnel, etc.). (2009)

- 3.4.2. Develop and implement evidence-based training curriculum and implementation strategy for targeted audiences (i.e. Department for Mental Health and Mental Retardation, Office of Inspector General surveyors, Comprehensive Care Centers, family caregivers, etc.). (2009)
- 3.4.4. Develop and implement an evidence-based training curriculum and implementation strategies for Long Term Care facilities. (2009)
- 3.4.5. Require mandatory training as part of DOCJT yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers). (2009)
- 3.4.6. Require mandatory dementia-specific training for emergency room staff including nurses, physicians and related services technicians such as radiology. (2009)
- 3.4.7. Increase training for State adult protective services workers on Alzheimer's/dementia. (2009)
- 3.4.8. Require training for providers and State staff associated with any of the Medicaid home and community based waivers. (2010)
- 3.4.9. Develop a portable certification program for para-professional direct caregivers with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer's and related dementias. (2010)
- 3.4.10. Work with the universities to develop specific training and recruitment options including:
  - a. The development of optimal training content standards for licensed health professionals; target Kentucky's professional schools to integrate it into curricula. (2010)
  - b. Create a "Bucks for Brains" program to recruit and train geriatric psychiatrists, geriatricians, and other geriatric medical specialists. (2012)
  - c. The development of residencies or fellowships for training of geriatric psychiatrists, geriatricians, and other geriatric specialists. (2012)
  - d. The development of a specific track on Alzheimer's and related dementias for medical students. (2012)



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**RECOMMENDATION 3.5**

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*Establish State Protocol on Appropriate Interface and Choices for Individuals with Alzheimer's Disease, Related Dementias and Their Families.*

**Strategies:**

- 3.5.1. Require the Unit and Council to develop a protocol detailing how to interface with individuals with Alzheimer's and related dementias and their families. The protocol should include appropriate placement options based on the stages of Alzheimer's and dementia related diseases. (2008)
- 3.5.2. Require the Unit and DAIL to provide training to staff within the Cabinet for Health and Family Services on the protocol including but not limited to adult protective services workers, guardianship/social workers, and staff from the Office of Inspector General and the Department for Mental Health and Mental Retardation on the protocol. (2009)
- 3.5.3. Require, through the Secretary of the Cabinet, that all Department staff utilize the protocol as an established Cabinet practice. (2009)

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**RECOMMENDATION 3.6**

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*Explore options to increase insurance coverage for individuals with Alzheimer's and Related Dementias*

**Strategies:**

- 3.6.1. Explore changes needed to ensure Medicaid eligibility for early onset dementia. (2009)
- 3.6.2. Explore potential for Medicaid waiver specific to Alzheimer's and Related Dementias. (2009)
- 3.6.3. Explore services and options available under private insurance entities. (2009)
- 3.6.4. Provide tax incentives for individuals who purchase long term care insurance. (2008)
- 3.6.5. Support the establishment of a Kentucky Long-Term Care Partnership Insurance Program. This partnership has been successfully piloted in California, Connecticut, Indiana, and New York. (2008)
- 3.6.6. Advocate for integrated systems of healthcare and support that are effective for individuals with Alzheimer's disease or related dementias and their

families. (e.g. disease management strategies, practice guidelines, home and community based care, hospice care and chronic care management). (2008)

3.6.7. Require mental health parity (2008)

3.6.8. Promote educational resources for better understanding of Long Term Care financing. (2008)

### **Programs and Services**

**Identified Challenge:** Lack of existing services, resources, and capacity to effectively serve individuals with Alzheimer’s Disease and Related Dementias.

**SJR 6 Goal:** Build capacity to support the service spectrum of both current and future individuals who will need effective supports and services for Alzheimer’s Disease and Related Dementias.

Kentucky’s current service array system resembles a collage rather than a continuum of care. Services are provided through a cadre of providers with disjointed funding sources, coordination and policy.

Upon review, it was determined that many of the issues and challenges prohibiting the development of a cohesive system of services and programs are related to three core factors:

1. State regulations and licensure requirements are prohibitive of “dementia friendly” approaches.
2. A lack of incentives for caregivers and providers to create quality initiatives.
3. Lack of appropriate strategies and programs to address behavior issues associated with dementia.

Regulations, licensure requirements and departmental policies and procedures are sometimes conflicting and often not considered “dementia friendly”, meaning they do not take into account the unique needs and stages related to dementia including early on-set. State regulations often inadvertently present barriers to quality care for this population.

The current array of institutional care options is rigidly sub-divided based on providers’ service capabilities rather than on the changing needs of individuals; this is particularly problematic for persons with dementia because of their reliance on environmental consistency for processing change.

Additionally, constant turnover in caregiver staff creates a hardship for the provider agency as well as the consumer and family member. One key reason for the turnover is the lack of career path and low pay for caregivers. Currently there is not a mechanism in place to support the development of a clear career path for direct care workers (caregivers). These two issues result in one of the greatest challenges to creating a continuum of care.

Kentucky has been remiss in developing new, evidence based innovations for serving this population. Institutional environments have been typically grounded in a “medical model” of care and current regulations governing facility design have the unintended effects of preserving the status quo and inhibiting innovation.

Finally, there are occasions when an individual’s behavior severity exceeds the capabilities of the long-term care facility and the surrounding community, leading to early and unnecessary discharge. Innovative resources in each setting would also assist with this challenge.

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### **RECOMMENDATION 3.7**

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*Institute State policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer’s Disease Related Dementias.*

#### **Strategies:**

- 3.7.1 Work with law enforcement to implement a coordinated protocol or swift and appropriate action upon report of a missing adult with dementia. (2009)
- 3.7.2. Offer tax credits to families for the purchase of locator devices. (2009)
- 3.7.3 Direct the Council to study new technologies that can help locate missing persons and make recommendations about implementation strategies. (2010)
- 3.7.4 Utilize the Council to evaluate State regulations on home care, adult day and home health to assure they are “dementia friendly”. (2008)
- 3.7.5. Explore changes in the certificate of need requirements in order to foster expansions of Alzheimer’s and dementia specific services. (2009)
- 3.7.6. Develop a process/protocol to permit persons with dementia to remain in their current living environment despite a change in their condition (e.g. challenging behaviors or other disease symptom) that under existing regulations might otherwise promote their move to a different level of care; this protocol should assure that the provider can adequately demonstrate that the person’s care needs can be safely and effectively met without the

disruption of moving. (2009).

- 3.7.7. Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior. (2008)
- 3.7.8 Develop by 2009 regulations or waiver protocol inviting the development of new approaches to facility design that are preserve resident safety, recognize the special needs of persons with memory loss and show promise for improving the quality of their lives. (2009)
- 3.7.9 Review the current Kentucky Medicaid programs to ensure “dementia friendly” approaches and policies. (2008)
  - d. Review the “Resource Utilization Groups” (RUGs) system to determine values of behavior management and evidenced based interventions.
  - e. Increasing opportunities for self determination
  - f. Identify challenges to admission and eligibility requirements
- 4.7.10 Review overlapping requirements for licenses for personal care homes and assisted living facilities such as medication management including oversight, assistance, administration and monitoring. (2010)

### **Research and Evaluation**

**Identified Challenge:** Lack of State support of Alzheimer’s research through Kentucky universities and other resources.

**SJR 6 Goal:** Build capacity to support Alzheimer’s research and evidence based practices specific to the populations residing and receiving services in Kentucky

Although Kentucky provides funds to Universities to support faculty positions in various capacities, monies are not designated for use in specific areas of research. Furthermore, Kentucky does not have any targeted funds to specifically support Alzheimer’s Disease research through Kentucky universities or other research and evaluation activities such as the implementation of evidence based practices, evaluation of evidence based practices specific to Kentucky populations or exploration of promising practices that may currently exist in the State.

While DAIL has successfully secured numerous grants during the past calendar year, funds to support implementation or further examination of existing evidence-based practices recognized by the Alzheimer’s Association have not been obtained. Currently, there is no information that supports the use of an evidence based training curriculum in Kentucky.

Finally, DAIL has recently collaborated with Sander's Brown Center on Aging and the Alzheimer's Association to explore outreach services for the African American Community by specifically targeting individuals who may have Alzheimer's Disease and Related Dementias as well as, the empirical evidence that may support the Best Friends model of care for individuals with Alzheimer's Disease who are being served in both a rural and urban Adult Day Center. These promising practices may soon become evidence-based practices that could serve as a national model of excellence.

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### **RECOMMENDATION 3.8**

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*Explore the designation of existing State funding supports of Alzheimer's research through Kentucky universities and other resources:*

**Strategies:**

- 3.8.1 Explore process for distributing State funds to University faculty and determine feasibility of designating State funds specifically toward Alzheimer's research. (2009)
- 3.8.2 Explore additional funding sources for Alzheimer's research through Kentucky universities and other resources. (2009)

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### **RECOMMENDATION 3.9**

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*Establish policies, procedures, and incentives to incorporate evidence-based practices into training, service, and program activities.*

**Strategies:**

- 3.9.1 Identify and promote wide use of evidence based practices through the development of an Evidence Based Practice Guide specific to Alzheimer's Care. (2008)
- 3.9.2 Explore changes needed to support the purchase and provision of evidence based practice training and education. (2008)
- 3.9.3 Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds. (2009)
- 3.9.4 Identify and explore ways to further evaluate existing evidence based practices with Kentucky's populations. (2008)

### **RECOMMENDATION 3.10**

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*Research and evaluate promising practices across various regions in Kentucky*

Strategy:

- 3.10.1 Continue exploring grant opportunities to provide empirical evidence of nationally recognized evidence-based practices as well as practices that are already occurring in the State (e.g., Best Friend's model of care). (2008)

## APPENDICES

## Appendix A

### Glossary of Terms

AAA	=	[Kentucky's] Area Agencies on Aging
AD	=	Alzheimer's Disease
ADC	=	Alzheimer's Disease Centers
AD/D	=	Alzheimer's disease and other dementias
AWARE	=	Alzheimer's Wandering and Rescue Education [program]
BRAiNS	=	Biologically Resilient Adults in Neurological Studies
CHD	=	Coronary heart disease
CHF	=	Congestive heart failure
COPD	=	Chronic obstructive pulmonary disease, including emphysema
DAIL	=	Department for Aging and Independent Living
DOCJT	=	[Kentucky's] Department of Criminal Justice Training
HUD	=	Housing and Urban Development
NIA	=	National Institutes on Aging
NIH	=	National Institutes of Health
RDAD	=	Reducing Disability in Alzheimer's Disease
REACH	=	Resources for Enhancing Alzheimer's Caregiver Health
RUGs	=	Resource Utilization Groups
SJR 6	=	Senate Joint Resolution Six
STAR-C	=	Managing Difficult Behaviors: A Standardized Intervention to Help Family Caregivers



## **Appendix B**

### **Senate Joint Resolution 6**

A JOINT RESOLUTION calling for a comprehensive state strategy to address the needs of persons with Alzheimer's disease and related disorders in the Commonwealth of Kentucky.

WHEREAS, Alzheimer's disease is a slow, progressive disorder of the brain that results in loss of memory and other cognitive function and, eventually, results in death; and

WHEREAS, because Alzheimer's is accompanied by memory loss, poor judgment, changes in personality and behavior, and a tendency to wander, individuals with this disease are at increased risk for accidental injury, getting lost, abuse, neglect, and exploitation; and

WHEREAS, one in ten persons over the age of 65 and almost one in every two people over the age of 85 has Alzheimer's disease or a related dementia; and

WHEREAS, over the past ten years, the number of Kentuckians with Alzheimer's and related dementia has risen dramatically to over 74,000 people and is expected to increase to over 97,000 by 2025, when baby boomers enter the age of greatest risk for Alzheimer's; and

WHEREAS, by 2005, the number of the baby boomer generation entering the age of greatest risk for Alzheimer's is expected to increase to over 97,000; and

WHEREAS, Alzheimer's disease takes an enormous toll on loving family members as caregivers watch the deleterious effects of the disease closely and often suffer more stress, depression, and health problems than caregivers of people with other illnesses; and

WHEREAS, Alzheimer's disease is considered to be early in onset if an individual is younger than age 65 when symptoms first appear in the 30s, 40s, and 50s; and

WHEREAS, new data shows that there may be half a million Americans under the age of 65 who have dementia or cognitive impairment at a early onset; and

WHEREAS, the Commonwealth of Kentucky recently undertook the Kentucky Elder Readiness Initiative (KERI) to examine its ability to meet the needs of a rapidly aging population and the Long Term Living Initiative to examine Medicaid and continuum of care services; and

WHEREAS, the Commonwealth of Kentucky needs to assess the current and future impact of Alzheimer's disease on Kentuckians and state systems, programs, and services to ensure an integrated, comprehensive, coordinated, and up-to-date strategy to address the needs of this growing segment of Kentucky's population; and

WHEREAS, within the Cabinet for Health and Family Services there is an Office on Alzheimer's Disease and Related Disorders and an Alzheimer's Disease and Related Disorders Advisory Council, which was established by statute; and

WHEREAS, the office and council are charged with overseeing policy and services affecting residents of Kentucky with dementia and their families and caregivers; recommending delivery of

services in the most effective and efficient manner possible to facilitate the needs of people with dementia and their caregivers; assisting with the dissemination of program and educational materials; promoting public and professional awareness and education of dementia and access to needed services and programs; and enhancing the quality of life for persons affected by Alzheimer's, and their caregivers; and

WHEREAS, currently state programs, resources, information and services serving this population are fragmented and many are out-dated;

NOW, THEREFORE,

Be it resolved by the General Assembly of the Commonwealth of Kentucky:

Section 1. The Kentucky Alzheimer's Disease and Related Disorders Advisory Council and Office are directed to assess the current and future impact of Alzheimer's disease on Kentuckians; to examine the existing services and resources addressing the needs of persons with Alzheimer's, their families, and caregivers; and to develop a strategy to mobilize a state response to this public health crisis.

Section 2. The Kentucky Alzheimer's Disease and Related Disorders Advisory Council shall include an examination of the following in its assessment and recommendations:

(1) Trends in state Alzheimer's population and needs, including the changing population with dementia, including but not limited to:

(a) State role in long-term care, family caregiver support, and assistance to persons with early-onset and early onset of Alzheimer's; and

(b) State policy regarding persons with Alzheimer's and developmental disabilities;

(2) Existing services, resources, and capacity, including but not limited to the:

(a) Type, cost and availability of dementia services;

(b) Capacity of public safety and law enforcement to respond to persons with Alzheimer's;

(c) Availability of home- and community-based resources for persons with Alzheimer's and respite care to assist families;

(d) Inventory of long-term care special dementia care units;

(e) Adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's and related dementia;

(f) Assisted living residential options for persons with dementia; and

(g) State support of Alzheimer's research through Kentucky universities and other resources; and

(3) Needed state policies or responses, including but not limited to recommendations 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.

Section 3. The Kentucky Alzheimer's Disease and Related Disorders Advisory Council is directed to submit a report of its findings and recommendations to the Kentucky General Assembly and the Governor no later than January, 2008.

## Appendix C

### Evidence Based Training Curricula or Caregivers of Individuals with Alzheimer's Disease and Related Dementias

***Managing Difficult Behaviors: A Standardized Intervention to help Family Caregivers (STAR-C).*** STAR-Caregivers (STAR-C) is a standardized intervention to help family caregivers identify, reduce, and manage difficult behavioral symptoms of their relative with Alzheimer's disease. STAR-C decreases both the symptoms and the caregivers' related feelings of stress, burden, and depression. Researchers conducting a rigorous study comparing a control group to STAR-C participants found the STAR-C caregivers reported that their relative with Alzheimer's disease had significantly fewer behavioral symptoms than were reported by caregivers in a control group. STAR-C caregivers also ranked their family member's quality of life higher than did caregivers in a control group. Additionally, STAR-C caregivers showed statistically significant reductions in depression, burden, and reactivity to their relative's behavioral symptoms. Before the intervention, 43% of the STAR-C caregivers scored as clinically depressed compared with 34% of caregivers in the control. After the eight in-home meetings, only 29% of the STAR-C caregivers scored as depressed, compared with 37% of the control group caregivers. At the end of the study, STAR-C caregivers were significantly less likely than the control group to be depressed; they were less likely to report feelings of burden; and they had fewer problems with sleeping.

***Making Sense of Memory Loss.*** Making Sense of Memory Loss is a training program intended to help families and other caregivers of people in the early stages of Alzheimer's disease. The Making Sense of Memory Loss program was developed by the Mather LifeWays Institute on Aging and the Greater Illinois Alzheimer's Association Chapter. The five training modules are: 1) overview of memory loss and related symptoms; 2) communication strategies; 3) making decisions; 4) planning for the future; and 5) effective ways of caring and coping. Evaluations of training results showed a statistically significant increase in the caregivers' knowledge about Alzheimer's disease from pre- to post-training and nine months later. It also showed a slight reduction in caregiver reports of being upset about the person and a slight increase in caregiver depression, both post-training and nine months later. The program developers believe the increase in depression may reflect the program's effect on caregivers' awareness of the person's condition and their new caregiving roles and responsibilities. Additional evaluations found statistically significant increases from pre- to post-training in caregivers' knowledge about Alzheimer's disease and confidence in their ability to provide care. The evaluations also found a statistically significant reduction in caregivers' reports of being upset about the person and no change in caregiver depression.

***The New York University Counseling and Support Intervention for Caregivers.*** An Evidence-Based Intervention for Caregivers of People with Alzheimer's Disease, the focus of the New York University (NYU) Counseling and Support Intervention for Caregivers is to diminish the negative impacts and increase the positive supportive elements of family caregiving. This is achieved through a combination of individual

counseling and additional support interventions, such as support groups and the availability of ad hoc counseling. Published articles provide evidence-based information that this intervention: (1) decreases caregiver depression, (2) decreases negative caregiver appraisals of behavior problems in the person with dementia, and (3) delays nursing home placement of the person with dementia. Thus far, the NYU Counseling and Support Intervention has proven effective for spouse caregivers. It is currently being tested with adult children caregivers.

Most recently, it has been found that receiving the NYU Counseling and Support Intervention leads to delayed nursing home placement of the person with dementia. Data analyses suggest that the median delay in placement is 557 days, or approximately 1.5 years. This extends a result found in 1996 that studied the first 206 participants in intervention and found a median delay of 329 days. Importantly, delaying nursing home placement of the person with Alzheimer's disease did not diminish caregiver well-being. Data indicates that participants were, in fact, able to keep their spouses at home longer as a result of improvements in the participants' well-being.

***Reducing Disability in Alzheimer's Disease (RDAD)*** The Reducing Disability in Alzheimer's Disease (RDAD) program provides exercise training for people with Alzheimer's disease who live at home and simultaneous training for their family caregivers about how to manage behavioral symptoms. The program is intended to reduce behavioral symptoms and depression and improve the person's physical functioning. Behavioral symptoms and fall-related fractures often result in nursing home placement for people with Alzheimer's disease. The RDAD program combines two interventions to address these problems. The behavioral research findings published in the Journal of the American Medical Association show statistically significant short- and long-term benefits for people in the treatment group. Three months after the RDAD program ended, people in the treatment group were exercising more; their physical functioning had improved, while the physical functioning of people in the control group had gotten worse; and people in the treatment group had decreased depression, while those in the control group had increased depression. Two years after the RDAD program ended, people in the treatment group still had better physical functioning than those in the control group. Only 19% of those in the treatment group had been placed in a nursing home because of behavioral disturbances, compared with 50% of those in the control group. (The last finding did not reach statistical significance.)

***Resources for Enhancing Alzheimer's Caregiver Health (REACH) I.*** Alzheimer's Caregiver Health (REACH) is a unique, multisite research program sponsored by NIH and the National Institute on Nursing Research. The primary purpose of REACH is to carry out social and behavioral research on interventions designed to enhance family caregiving for AD and related disorders. Specifically, REACH has two goals: to test the effectiveness of different interventions and to evaluate the pooled effect of REACH interventions overall.

Although the interventions were derived from diverse theoretical frameworks, they are all consistent with basic health stress models in which the goal is to change the nature of

specific stressors (e.g., problem behavior of the care recipient), their appraisal, and/or the caregivers' response to the stressors. All of the REACH interventions were guided by detailed treatment manuals and certification procedures that ensured that the interventions were delivered as intended and consistently over time at each site.

***Resources for Enhancing Alzheimer's Caregiver Health (REACH) II.*** The design of the REACH II intervention was guided by a careful consideration of existing research literature as well as the experience and findings from REACH I. Because caregiving presents multiple challenges that are not easily addressed, there is no single, easily implemented, and consistently effective method for achieving clinically significant effects among caregivers or care recipients.

Researchers have achieved small to moderate statistically significant outcomes on a wide variety of indicators such as depressive symptoms, burden, and other indicators of psychological well-being. The lack of strong findings is in part due to the misapplication of intervention approaches borrowed from medical and psychotherapeutic approaches. For example, although most caregivers have elevated levels of depressive symptoms they do not meet criteria for clinical depression. Thus, unless one targets specific subgroups of caregivers who are clinically depressed, the ability to demonstrate large effects is constrained by the moderate level of the problem being addressed and the limited range of improvement possible. In general, caregivers can be characterized as having problems in multiple and interrelated domains, which exist at varying, but typically not extreme, levels of intensity. The intervention approach selected for this study is based on this assumption and is designed to maximize outcomes in multiple different domains by tailoring the intervention to respond to individual variation in risk. For example, persons in active treatment who have minimal problems with depression will receive only a small dose of the intervention component designed to enhance emotional well-being. This will enable the interventionist to concentrate on those areas where risk factors are higher.

***Savvy Caregiver.*** Savvy Caregiver is intended to train families and others for the unfamiliar role they face as caregiver for a relative or friend with Alzheimer's disease or another dementia. The program focuses on helping caregivers think about their situation objectively and providing them with the knowledge, skills, and attitudes they need to manage stress and carry out the caregiving role effectively. The curriculum was specifically developed for targeting rural caregivers.

An evaluation of Savvy Caregiver found statistically significant positive outcomes for caregivers who participated in the program vs. those in the control group with respect to the caregivers' beliefs about caregiving, their reactions to the behavioral symptoms of their care recipient, and their feelings of stress and burden (Ostwald et al., 1999; Hepburn et al., 2001). This evaluation was conducted in an academic setting where the program was delivered by its developers.

## **Appendix D**

### **DAIL Research and Program Evaluation Activities**

#### **Nursing Home Diversion Grant**

This 18 month, \$333,000 grant employs the consumer driven model to divert non-Medicaid clients from Nursing Home residency by allowing the client to hire their own caregivers to provide in home care. Pilot sites are Big Sandy and Kentucky River Area Agencies on Aging and Independent Living.

#### **KY Quality Dementia Care Project**

This \$289,000 one year grant is a multi-focal method to advance quality of services and supports for those with and those caring for individuals with Alzheimer's Disease and related dementias. Our staff will assist with an evaluation of the Best Friends Approach to Alzheimer's Care for inclusion as evidence based practice. Second, we will provide dementia capable training for staff providing services to such individuals. Third we will provide staff to complete a legislated dementia specific State plan. The final piece of Kentucky's Quality Dementia Care Project will be to pilot a consumer directed approach utilizing clients on the waiting list for State funded Homecare and Adult dementia capable staff, evaluate the "Best Friends Approach to Dementia Care" in an Adult Day Care Center in a rural impoverished area and one in a predominantly African American community in an urban area. Evaluate the ability of families to delay nursing home placement by using a self directed approach to caring for their family member.

#### **Model Legal Service Developer Grant**

Utilizing the Model Legal Service Developer Grant, Kentucky plans to strengthen the relationship between the legal services provider and older Kentuckians, enabling older Kentuckians in underserved areas of the State to have better success in receiving needed legal services. This will be accomplished through improving collaboration between both public and private legal service providers through a single point of entry. This grant is \$100,000 per year for three years.

#### **Real Choice Systems Change Grant: State Profile Tool, Assessing a State's Long-Term Care System**

DAIL was awarded \$500,000 over a 3 year period to systematically and comprehensively assess its long-term living system through the completion of a State Profile Tool. This assessment will provide information to stakeholders about our success toward rebalancing and identify gaps and opportunities for improved coordination among long-term support programs across aging and disability areas. Additionally, Kentucky will actively engage with CMS to develop national balancing indicators and enhance data system capacity that will allow for cross-State comparisons.