

**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 Actions**

2017 Update

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

April 5, 2017
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Introduction

Alzheimer's disease is the sixth leading cause of death for people in the United States and the fifth leading cause of death for those over the age of 65. Between 2000 and 2014, deaths as a result of Alzheimer's disease have increased by 89%, while other major causes of death – such as heart disease - have decreased. In 2017, there are approximately 70,000 Kentuckians age 65 and over living with Alzheimer's disease, and this number is expected to rise to 86,000 by 2025. The fragmented and out-dated resources, information, and services available in Kentucky will further impede the state's response to the Alzheimer's disease epidemic.

In 2008, 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 turn, "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 Actions" was produced. This report detailed findings of the assessment, issues and challenges, corresponding recommendations, and strategies to implement change. In years since, shifting demographics, healthcare reforms, evolving services, among other factors, have changed the face of Alzheimer's disease and its associated challenges in Kentucky.

Following is the 2017 response to the assessment related to SJR 6, with adapted recommendations and updates to each topics' current state. This response includes seven recommendations with strategies revolving around the following topics: Office on Alzheimer's Disease and Related Disorders, family caregivers, statewide data collection, dementia-specific training, services, and program activities, patient interface, insurance coverage, and Kentucky state policies.

Office on Alzheimer's Disease and Related Disorders

The Office on Alzheimer's Disease and Related Disorders began in 1996 under the Cabinet for Human Resources. KRS 194A.601 established the office within the Cabinet for Health and Family Services on July 14th, 2000. Its purpose was to oversee policy and services that affected residents of Kentucky with dementia as well as their caregivers and/or families. Creation of the Office also called for a full time director to orchestrate and monitor the operational details of the office. As of 2017, the Office on Alzheimer's disease and Related Disorders exists; however lack of funding has prevented the office from becoming fully viable. Since there are no specific employees for the Office yet, there has been no expansion to include policy, research, and coordination of services.

The Alzheimer's Disease and Related Disorders Advisory Council was created at the same time as the Office. At its origination, the Council was intended to report to the Office. In 2017, the Council is a fully functioning group, composed of 15 members that meet to establish quarterly goals and outcomes related to dementia as well as assist with information dissemination.

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

3.1.1 Establish the "office" to become the Alzheimer's disease and Related Disorders Unit working in conjunction with the council.

3.1.2 Obtain specific State general funding to hire a full time coordinator for the Alzheimer's and Related Dementias Unit and expand the Unit's role to include policy, research, and coordination of services.

3.1.3 Require the Unit to conduct the following activities:

- 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 association, and general public
- 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

Family Caregivers

Family caregivers are a critical part in keeping older Kentuckians out of long term facilities and avoiding unnecessary hospitalizations. In December 2014 Research Memorandum No.517, titled "Support for Family Caregivers of Elders", was drafted by the Legislative Research Commission in part with The Department for Aging and Independent Living (DAIL). Findings from the report were as follows:

- Approximately 735,000 Kentuckians are caregivers helping family members to age in a home setting rather than in an institutional setting.
- Aging in a home setting with appropriate supports for seniors and family caregivers may be more cost effective than nursing home care. Kentucky's Medicaid program pays

approximately \$48,000 per year for a nursing home bed compared to \$15,000 for in-home supports

- Transportation assistance for seniors to make health care appointments and perform household errands is not consistently available across the state. Most caregivers provide all transportation needs for their family member.
- Many family caregivers do not receive any state-funded supports. They are often unaware that services exist or cannot afford services that are available. There are waiting lists for most state-funded services and supports for seniors and family caregivers. More support for the Area Agencies on Aging and Independent Living could help more caregivers provide care for their family members.
- The majority of seniors indicate a preference to age in a home setting rather than in an institutional setting.
- Kentucky ranks low nationally compared to other states on indicators of supports for family caregivers such as respite care, family and medical leave, and home health and personal care services.
- Caregivers are often not included in transitional care planning when their family members are discharged from a hospital stay
- There are shortages of personal care and home health professionals, particularly in rural areas

The Department of Health and Human Services oversees the Department of Aging and Independent Living (DAIL), the agency responsible for administering statewide programs for elderly populations and their caregivers. The state funded programs administered by DAIL which provide relief for caregivers, including those with elders with dementia, sustained a 4.5% cut in the last quarter of the 2016 fiscal year and are slated to undergo a 9% cut in 2017. State and local funding of DAIL is primarily on behalf of the Older Americans Act (OAA) and the Center for Medicare and Medicaid Services (CMS). Current state funded programs for caregivers include: Aging and Disability Resource Centers, caregiver support services, guardianship, Hart-Supported Living, homecare, personal care attendant program, and senior citizen centers.

Local administrative agencies as established by DAIL are Aging and Disability Resource Centers (ADRCs). In 2014, Kentucky created 15 ADRCs in each of the Area Agency on Aging and Independent Living sites that streamlined access to long-term care for people of all ages, incomes, and disabilities to get information on the full range of long term support options. As of 2017, the ADRCs are fully functioning.

There are five CMS waivers that affect the elderly and/or their caregivers: Acquired Brain Injury/Acute, Acquired Brain Injury/Long-Term Care, Home and Community Based (HCBS), Michele P., and Supports for Community Living. The HCBS waiver exists to support disabled individuals in either returning or remaining in their homes. Individuals who are elderly or disabled, meet nursing level facility of care, or are financially eligible for Medicaid are eligible for services under the Waiver. Assessment, reassessment, case management, home

adaptation, adult day health care, homemaker, personal care, attendant care, and respite care are all offered services. A Consumer Directed Option (CDO), now known as participant Directed Services (PDS), is also included, giving individuals the freedom to select their own non-medical waiver services including support broker, homemaker, personal care, attendant care, unskilled respite care, and goods and minor home adaptation. CMS has made changes to language in its HCBS waiver that impacts funding and brick and mortar centers, with a general intent of separating service provisions between care assessment and planning. It establishes requirements for the qualities of home and community based settings, inhibiting respite or community-care services from being provided in settings deemed “institutional”. The ruling required States to submit an implementation plan with a 5 year transition period upon approval. Kentucky’s was approved on August 1st, 2016.

In 2010, HB 411 was introduced regarding an income tax check-off to fund education and training for healthcare workers and informal caregivers, counseling for families of persons with the disease, respite services, and technological assistance for persons with the disease. In 2011 and 2012, tax check-off bills were drafted but not picked up.

Recommendation 3.2 Increase and Improve support for family caregivers.

- 3.2.1 Request an increase in the Alzheimer’s Program Development and Implementation line item in the State budget.
- 3.2.2 Utilize the council and stakeholder community to revise the current definition, eligibility, and service requirements for the provision of respite.
- 3.2.3 Maintain a system of care coordinators and benefit counselors in each of the 15 ADD regions.
- 3.2.4 Develop incentives beyond tax incentives for caregivers.
- 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.
- 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 to accommodate anticipated growth in demand.

Statewide Data Collection

The CDC's Behavioral Risk Factor Surveillance System (BRFSS) included the cognitive and caregiver modules in Kentucky was applied for by the Alzheimer's Association in 2012, 2015 and 2016 with funding by the Alzheimer's Association through a CDC grant in 2012 and 2015 and with funding provided by DAIL in 2016. The Alzheimer's Association will again apply for modules in 2018. The cognitive model collects demographic, geographic, and socioeconomic data. This module is subjective to cognitive decline, questioning participants about their own memory and its impact on their daily life. The caregiver module focuses on collecting data regarding caregivers' personal health and greatest care needs. This module serves as a baseline to experiences of dementia caregivers with those of other conditions. Access to this information is available through the Kentucky Cabinet for Health and Family Services, the Center for Disease Control and Prevention, and the Alzheimer's Association. The data is currently used to analyze trends, formulate legislation, monitor progress of prevention efforts, educate the public, and provide data for budget and grant preparation. In 2005, a statewide data system called SAMS was implemented to track all of the services that the Agency on Aging and Independent Livings (AAILs) provides. Information is collected through local ADRCs and is then able to be accessed by the State for reports or dissemination. At this time, information pertaining to Alzheimer's/dementia is collected under a "Disability" title. The Kentucky Department for Public Health is also a reliable source for data collection. Although data sources in the state do exist, there are gaps in the data being collected as well as room for increased organization coordination.

Recommendation 3.3 Monitor a statewide data collection system.

3.3.1 Collect data and monitor at a minimum the following data

- The prevalence of dementia related diseases across the Commonwealth
- The prevalence of dementia related diseases by county
- The prevalence of early onset dementia and related diseases across the Commonwealth
- The prevalence of inpatient geriatric psychiatry beds
- The availability of geriatric services and specialists
- The availability of dementia related services and supports
- The availability of assessment services for Alzheimer's and related dementias
- The number and location (county) of Kentuckians who are currently providing care in their home to a family member

Dementia-Specific Training, Service, and Program Activities

Several entities have produced curriculum for professional training. Hand in Hand: A Training Series for Nursing Homes was developed and widely disseminated in 2013 through Centers for Medicare and Medicaid services. Stress Busting for Caregivers and Treatment as Prevention (TAP), both of these evidence based programs recognized and grant-funded by the NIA have been used by the Bluegrass Area Development District (BGADD) ADRC for training purposes. The Alzheimer's Association has produced best practice guidelines and recommendations for long-term care specific to Alzheimer's Care as well as provides online training programs for frontline staff. Currently, University of Louisville is conducting a study titled the Geriatric Workforce Enhancement Program (GWEP) funded by the Health Resources and Services Administration (HRSA). It is addressing workforce cultural competency and availability, challenges in chronic disease reduction, rural communities' capacity to promote health, and the need for Alzheimer's disease and related dementias (ADRD) supportive education and resources. The GWEP consists of four programs: care coordination, geriatrics workforce education training, grassroots community development, and the creation of Alzheimer's and Dementia friendly communities. This study is expected to be complete within the next year.

Resources for care coordination and training are available, however policy requiring their implementation has not been successful. KRS Chapter 194A was introduced in 2015 and required all nurse-aids at long term care facilities to participate in dementia-specific training upon orientation, as well as completed 5 hours of training annually. The bill was heard in the house but not passed. In 2012-2014, Legislative session passed a resolution encouraging all first responders to receive at least one hour of Alzheimer's and related dementia training per year. In 2015, HR 46 urged state police, city police, county sheriffs and deputies, firefighters, and emergency medical services personnel in cities of 25,000 or more to receive one hour of training annually on Alzheimer's disease and other forms of dementia. It was disseminated to the Commissioner of the Department of Kentucky State Police, the Executive Director of the Kentucky Board of Emergency Medical Services, and to each local police department, county sheriff's office, and local fire department. The training is not mandated or enforced.

Recommendation 3.4 Promote policies and procedures that effectively incorporate proven practices related to dementia-specific training, service, and program activities for services providers and stakeholders.

- 3.4.1 Optimize use of up to date training resources to targeted audiences across the state.
- 3.4.2 Increase training for providers and state staff associated with any of the Medicaid home-and-community based waivers.

3.4.3 Require mandatory dementia-specific training for emergency room staff including nurses, physicians, and related services technicians.

3.4.4 Support and encourage training and subsequent provision of evidence based practices in programs and services supported by State funds and local jurisdictions.

3.4.5 Identify and explore ways to further support evaluation, purchase, and provision of promising and existing evidence based training and education among Kentucky's populations.

Patient Interface

The Alzheimer's Association has developed a comprehensive "Cognitive Impairment Care Planning" protocol and makes it available to facilities and physicians. The protocol involves a comprehensive exam and interview, typically in the presence of a caregiver or family member. The protocol also extensively details the G0505 Medicare Code that allows for reimbursements in clinical care visits that result in a comprehensive care plan. This allows for physicians or other related health care providers to deliver a service to ensure a higher quality of life at no additional cost. All Medicare beneficiaries who are cognitively impaired are eligible.

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

3.5.1 Require the Unit and Council to utilize 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.

Insurance Coverage

As of 2013, Kentucky became part of the Affordable Care Act's Medicare/Medicaid expansion program. Kentucky, as one of the first states to adopt the program, saw immense success. From 2013 to February 2015, there was a 105% increase in Medicaid enrollment and the uninsured rate dropped from 14.3% to 6%. In relation to Alzheimer's and dementia related disorders, the expansion showed significant progress in health care among populations located in poorer zip codes.

As part of the expansion, Kentucky passed multiple bills in favor of caregivers and individuals with dementia. HB 144 was introduced in 2015, and amended in the same year. It created a presumptive eligibility pilot for Medicaid home care services, providing up to 60 days of non-medical support services while an application for benefits is pending. It also required the

Department for Medicaid Services to make a final determination within 45 days of the receipt of a completed form. The later amendment established the Hospital-To-Home transition pilot program to provide these home care services, with the same provisions. SB 129 was passed in March 2017, establishing a process for contacting and providing instructions to lay caregivers upon discharge from a hospital. Additionally HB 95, an act relating to telehealth services, was signed into law in 2015 and requires the Department for Medicaid Services to submit a waiver or waiver amendment to the Centers for Medicare and Medicaid Services in order to provide coverage for home telemonitoring services and direct-to-patient telehealth services.

Benefits of the Medicaid expansion are in jeopardy with recently approved healthcare reform. On June 22nd, 2016 Kentucky Governor, Matt Bevin, proposed HEALTH (Helping to Engage and Achieve Long Term Health). HEALTH is a Medicaid waiver, largely refuting the Medicaid expansion implemented in 2013. Traditional benefits lost in the waiver include: dental, vision, hearing, private nursing, allergy testing, retroactive eligibility, and transportation for non-emergency care. The waiver would also include income based premiums, with required co-pays for individuals with unpaid premiums and a penalty for unnecessary Emergency Room visits or missed appointments. There is a potential six month lockout period and an additional community engagement requirement. The waiver excludes individuals over the age of 65, in an institution, and those who receive services through Michelle P, Acquired Brain Injury, Supports for Community Living, and Home and Community-Based Services. With the approval of this waiver, the Center on Budget and Policy Priorities estimates that 86,000 Kentuckians will lose insurance coverage within the first five years. Additionally, the Center for American Progress predicts a loss of 40,000 jobs and \$30 billion in economic activity.

Recommendation 3.6 Explore options to increase insurance coverage for individuals with Alzheimer’s and related dementias.

3.6.1 Support and Protect Medicaid eligibility and Alzheimer’s specific waivers for individuals with early onset Alzheimer’s disease or Related Dementias

3.6.2 Advocate for integrated systems of healthcare and support that support mental health parity and 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).

State policies and procedures

The National Silver Alert Program (H.R. 6064) was enacted in 2008. The Act allowed for creation of criteria, resources, and guidance to provide to state and local governments, law enforcement agencies, and other involve agencies in addressing missing adults aged 18 or older diagnosed with a mental disability. In compliance with the Act, Governor Steve Beshear signed Senate Bill 125, creating the Golden Alert System system in Kentucky. The Golden Alert is administered by the Kentucky Division of Emergency Management (KYEM) and outlines a communication network dependent on the amount of time a person has been missing. Although escalation of reports are outlined in time increments, there is no requirement to delay report of a missing person by any regency receiving notification.

The Alzheimer’s Association provides a 24/7 nationwide emergency response system for individuals with dementia, MedicAlert ® + Alzheimer’s Association's Safe Return ®. When an individual goes missing, caregivers can call an emergency response line to report it. A community support network is activated, notifying all relevant agencies in the area of the disappearance and pertinent medical information. Conversely, enrolled individuals are provided a bracelet or pendant with the emergency line number and critical medical information engraved so in the event they are located by a citizen or emergency personnel, caregivers can be contacted. Location technologies such as GPS systems used to protect against wandering are widely available although cost can be prohibitive to some families as they remain in the private marketplace.

Care options for individuals with Alzheimer’s and dementia include, Adult Day Center, in-home care, residential care (retirement housing, assisted living, nursing homes, Alzheimer’s Special Care Units SCUs/Memory Care Units, Continuing Care Retirement Communities (CCRC)), respite care, and hospice care. Kentucky Medicaid covers long-term care in Nursing Facilities and Intermediate Care Facilities for Individuals with Disabilities. Coverage for other care options are dependent on waiver eligibility.

Recommendation 3.7 Enhance state policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer’s disease and Related Dementias.

3.7.1 Utilize the Council to evaluate state regulations on home care, adult day and home health, to assure they are “dementia friendly.”

3.7.2 Monitor and give recommendations that address persons with dementia ability 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 ensure that the provider can adequately demonstrate that the person's care needs can be safely and effectively met without the disruption of moving.

3.7.3 Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behaviors.

3.7.4 Review the current Kentucky Medicaid programs to ensure "dementia friendly" approaches and policies, and identify challenges to admission and eligibility requirements

3.7.5 Support and encourage the evolution and application of best practice for persons with dementia living in personal care homes and assisted living facilities.

Conclusion

Ensuring that the needs of persons with Alzheimer's and dementia and their caregivers' are being considered and met in the state of Kentucky will involve progression on many fronts. Addressing Alzheimer's disease will require responding as quickly and comprehensively as the disease is occurring. Establishment of a unified Alzheimer's disease and Related Dementias Unit within DAIL and the Alzheimer's Disease and Related Disorders Council will support the progression of advocacy and collaborative action. An organized Unit and Council will ensure the maintenance and expansion of services and supports, particularly with the tentative state of Medicaid/Medicare coverage. That being said, as there is a current lack of funding for a unit position, the council can act as a strong resource for DAIL around issues of dementia that continue to affect the people of the Commonwealth.

With the impending revision of Kentucky's Medicaid expansion, coverage is in danger of being decreased. Caregivers are also adversely by these changes. Respite, care coordination programs, and financial support will be at an even higher demand and without funding cannot operate. And much of this requires a competent and prepared workforce. Implementation of mandated training and interface protocols will promote a universal and evidence based approach to care. Ultimately, ensuring that state policies are conducive to the highest level of care and safety for individuals with Alzheimer's and related dementias should be of high priority. The state of Kentucky has the capacity to meet Alzheimer's disease head on, and has already proven successful in implementing several recommendations laid out in the original 2008 Alzheimer's disease state plan. However, a more aggressive stance is needed to ensure that the rise in people living with dementia (86,000 with Alzheimer's type alone by 2025) and their loved ones is met with appropriate expertise, support and regulatory environment.

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