



December 3, 2012

The Honorable David Dewhurst
Lieutenant Governor of Texas
P.O. Box 12068
Austin, Texas 78711

The Honorable Joe Straus
Speaker, Texas House of Representatives
P.O. Box 2910
Austin, Texas 78768

Dear Lieutenant Governor Dewhurst and Speaker Straus:

Pursuant to House Resolution 1978, 82nd Legislature, Regular Session, the Joint Interim Committee to Study Alzheimer's Disease was established. The Committee has carefully considered all of the testimony received on this issue and submits this report. We look forward to continued discussions on the important topic of Alzheimer's Disease and the state's response during the 83rd legislative session.

Respectfully submitted,

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Senator Jane Nelson, co-Chair

Handwritten signature of Bob Deuell in cursive.

Senator Robert Deuell

Handwritten signature of Eddie Lucio, Jr. in cursive.

Senator Eddie Lucio, Jr.

Handwritten signature of Robert Nichols in cursive.

Senator Robert Nichols

Handwritten signature of Judith Zaffirini in cursive.

Senator Judith Zaffirini

Handwritten signature of John Zerwas in cursive.

Representative John Zerwas, co-Chair

Handwritten signature of Helen Giddings in cursive.

Representative Helen Giddings

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Representative Linda Harper-Brown

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Representative Susan King

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Representative Marisa Marquez

Section I: Background

Alzheimer's Disease (AD) is a progressive, age-related, terminal, and currently irreversible disease that afflicts the brain, causing problems with memory, thinking, and day-to-day functional abilities. The disease is characterized by decline in cognitive, behavioral, and physical abilities that can become severe enough to render its victims completely dependent upon caretakers.¹

More than 5,000 Texans die from the disease annually and approximately 340,000 Texans are currently living with it.² This number is expected to reach 470,000 by 2025³ and double by 2050.⁴ The prevalence of AD increases with age: while 13% of people age 65 and over have AD, over 43% of people age 85 and older have the disease.⁵ As the proportion of Texans who are 65 and older continues to increase, so will the number of Texans with AD.

Texas has successfully supported AD planning and research through the establishment of institutions such as the Texas Council on Alzheimer's Disease and Related Disorders and the Texas Alzheimer's Research and Care Consortium (TARCC), a research collaborative. Individuals with AD and their family members are able to access services and supports such as long-term and respite care through the Department of Aging and Disability Services (DADS) and the Health and Human Services Commission (HHSC).

Section II: Analysis

Health Impact of Alzheimer's Disease in Texas

The health impacts of AD are devastating for the hundreds of thousands of Texans who suffer from it. AD is the most common form of dementia, accounting for 60-80% of dementia cases. Difficulty remembering names and events, apathy, and depression are early clinical symptoms of AD. Later stages of the disease are characterized by impaired judgment, disorientation, confusion, behavior changes, and difficulty speaking, swallowing and walking.⁶ Although the cause of AD is unknown, most researchers agree that it develops as a result of multiple factors including changes in brain functioning that begin as many as 20 years prior to the appearance of symptoms. The greatest risk factor for developing AD is age, although AD is not a normal part of aging. Other risk factors for developing AD include a family history of the disease, a diagnosis of mild cognitive impairment (MCI), cardiovascular disease risk factors, and specific genetic mutations. Unfortunately, there is currently no cure for AD and no treatments that have been proven to prevent the development or progression of the disease.⁷

Economic Impact of Alzheimer's Disease

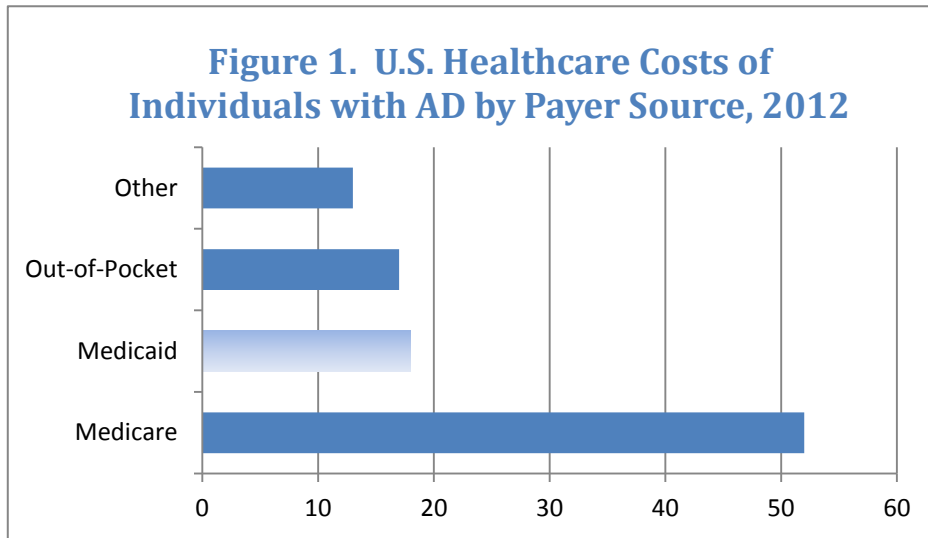
The economic impact of AD can be divided into two major components: healthcare costs of those with AD and costs associated with caregivers of individuals with AD.

Healthcare Costs

The health impacts of AD manifest themselves in part through significantly higher healthcare costs. A 2008 study found that the healthcare costs of Medicare beneficiaries with AD were three times greater than those of Medicare beneficiaries without AD in the same age group.⁸

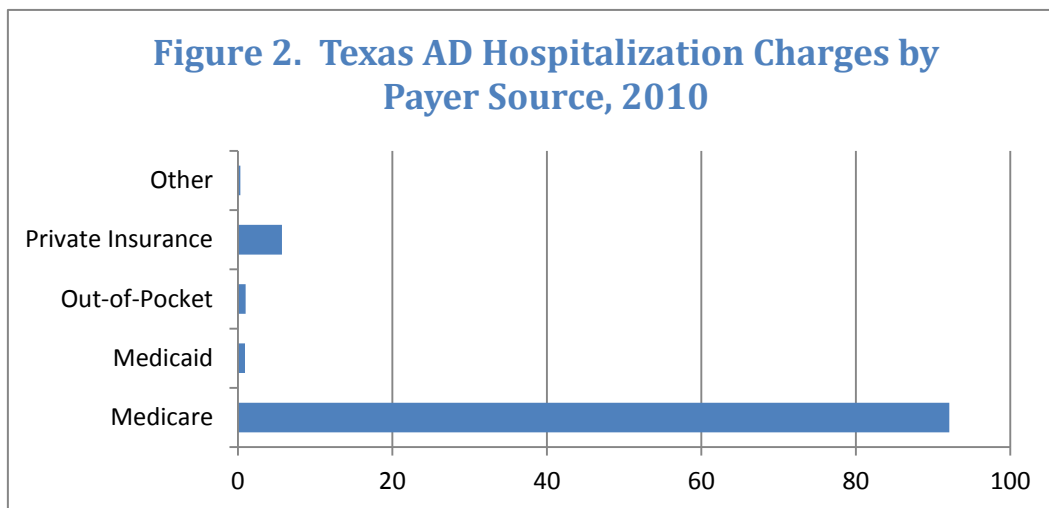
National Cost Estimates: National costs of healthcare for Americans 65 or older with AD were estimated to be \$200 billion in 2012. This number includes the cost of acute care, long-term care, and hospice care. Over half (52%) of these costs are paid by Medicare, 18% by Medicaid,

17% out-of-pocket, and 13% by other sources such as private insurance and uncompensated care.⁹



Texas Cost Estimates: There are no Texas-specific AD healthcare cost estimates. However, there are some data collected on the state level that provide a glimpse into the level of AD healthcare costs in Texas.

- **Hospitalizations:** The costs of hospitalizations of individuals with AD in Texas totaled \$65 million in 2010. 92% of these costs were paid by Medicare, 5.7% by private insurance, 1% out-of-pocket, 0.9% by Medicaid, and 0.3% by another source.¹⁰



- **Long-Term Care Enrollment:** Based on DADS' collection of data on enrollees in their Nursing Facility and Community-Based Alternatives (CBA) waiver programs, 22% of Nursing Facility enrollees had a diagnosis of AD, while 11% of CBA waiver enrollees

had a diagnosis of AD.¹¹ Using the monthly costs of providing services to AD patients in these two programs, it is estimated that individuals with a diagnosis of AD enrolled in either the Nursing Facility or the CBA Waiver Program cost about \$44.8 million per month, or \$537.6 million annually.¹²

Figure 3. Estimate of Monthly Cost of Providing Care to AD Patients in the Texas Nursing Facility and CBA Waiver Programs¹³

Program	Total Number Paid Enrollees	Number Paid Enrollees with AD Diagnosis	Alzheimer's Diagnosis (%)	Average Monthly Cost per AD enrollee	Total Monthly Cost of AD-diagnosed enrollees
Nursing Facility	62,224	13,468	22%	\$2,942	\$39.6 million
CBA Waiver	23,763	2,651	11%	\$1,954	\$5.2 million
<i>Total</i>	85,987	16,119	19%	\$2,780¹⁴	\$44.8 million

Caregiver Costs

In addition to the costs of providing healthcare for patients with AD, there are costs associated with caregivers. Caregivers assist individuals with AD in performing essential daily tasks such as eating, dressing and bathing; provide transportation; manage and administer medications; complete household chores; and manage the individual's legal and financial affairs. Caregivers, often family members, are typically unpaid for their services. In 2011, 1.27 million unpaid caregivers in Texas provided over 1.4 billion hours of unpaid care, at an economic value of \$17.5 billion.¹⁵ This estimate, however, does not account for productivity losses and absenteeism among caregivers who are also working full-or part time jobs while providing caregiving duties.

The stress of providing caregiver services takes its toll on the health and well-being of caregivers. In 2011, DADS funded the collection of data on caregiver health through the Behavioral Risk Factor Surveillance System (BRFFS) annual survey. The data showed that about 26% of primary caregivers had fair or poor overall health, and nearly 40% of caregivers reported that their mental health was not good for at least five days of the past month.¹⁶ On average, caregivers' healthcare costs are about \$587 higher annually than those of non-caregivers. For Texas' estimated 1.27 million unpaid caregivers, this translates to increased healthcare costs of about \$625 million each year.¹⁷

Inventory of Current Infrastructure, Programs, Capacity and Funding

Texas has established a variety of entities and programs to support AD planning, research, and caregiver support. The state also supports an AD program at the Department of State Health Services (DSHS).

Texas Alzheimer's Disease Program

The Texas Alzheimer's Disease Program at DSHS was established in 1987 to provide information and support to individuals with AD, their families, and long-term care providers.¹⁸

The program is limited in scope, with an annual budget of nearly \$100,000 and the following primary functions:

- Providing administrative support to the Texas Council on Alzheimer's Disease and Related Disorders;
- Operating a toll-free helpline that annually connects 2,400 individuals suffering from AD and their family members to services and supports; and
- Maintaining a website featuring information about AD, options for care, and lists of local Alzheimer's Association chapters as well as licensed nursing facilities and assisted living facilities certified to provide specialized AD care. More than 7,200 consumers access this website each year.¹⁹

Texas Council on Alzheimer's Disease and Related Disorders

The Texas Council on Alzheimer's Disease and Related Disorders, established in 1987, coordinates statewide strategic planning to address AD, serves as the state's advocate for persons with AD and their caregivers, and encourages and supports AD research.²⁰

- *Planning:* The Council, along with AD researchers, advocates, and healthcare and support service providers from across the state, developed a five-year strategic state plan for addressing AD in Texas. The plan, *A Comprehensive Plan for Addressing the Burden of Alzheimer's Disease in Texas: 2010-2015 Texas State Plan on Alzheimer's Disease*, serves as a blueprint for meeting goals to improve and advance brain health and AD prevention, research, disease management, caregiver support, and state and local capacity to address AD.²¹
- *Advocacy:* In their advocacy role, the Council provides ongoing guidance to state agencies on program and policy development regarding AD. For example, the Council advises HHSC's Pharmaceuticals and Therapeutics Committee on the inclusion of AD treatment medications in the Medicaid Preferred Drug List.²²
- *Research Support:* The Council also provides ongoing administrative support and guidance to the TARCC (Research Consortium). The Texas Legislature directed the Council to create the Consortium in 1999 through House Bill 1504 (Goolsby, 76R).²³

Texas Alzheimer's Research and Care Consortium (TARCC)

The TARCC was established to advance AD research and increase collaboration among AD researchers at institutions of higher education across the state.²⁴ Consortium members include the Baylor College of Medicine in Houston, Texas Tech University Health Sciences Center in Lubbock, the University of Texas Southwestern Medical Center in Dallas, the University of North Texas Health Science Center in Fort Worth, and the University of Texas Health Science Center in San Antonio. Each of these institutions operates a research institute focused on AD and/or aging research.²⁵

- *Texas Alzheimer's Data Bank:* The Research Consortium's enacting legislation required the establishment of a patient database, known as the Texas Alzheimer's Data Bank, that includes biographical and genetic data from thousands of volunteers that is used to support Consortium members' research initiatives. The Data Bank contains standardized

clinical, neuropsychiatric, genetic, and blood biomarker data from more than 2000 volunteers from across the state. Volunteers either have a diagnosis of AD, a diagnosis of mild cognitive impairment (MCI, which is a risk factor for developing AD), or have no signs of MCI or AD and serve as control subjects. Volunteers provide follow-up data through annual interviews and blood samples, allowing analysis of disease progression from year to year. The longitudinal nature of the Consortium's studies is a key strength of the Data Bank, which is stored at UT Southwestern. The Data Bank is accessible to all Consortium member researchers and has led to a variety of cutting-edge research, including the development of a blood test to predict AD which is currently undergoing additional research and validation. Other research made possible by the Data Bank include the discovery of genetic variations associated with the development of AD and evaluation of the connection between diabetes and AD.²⁶

- *Outreach:* As part of its statutory requirement, the Consortium, in coordination with the Alzheimer's Association and the Council, must develop and distribute educational materials that inform patients, caregivers and health care professionals of any research projects and therapeutic trials open for participation.
- *Funding:* The Legislature has provided funding to support the Consortium's research efforts since 2005, as shown in Figure 4. In addition to the dedicated General Revenue appropriated to the Research Consortium, the state invests additional funding in AD research through appropriations to the health-related higher education institutions. Each of the member institutions of the Consortium operates an institute or center focused on aging and/or AD and dementia, which are supported by state, federal, and in some cases private funding. One of these centers, the Alzheimer's Disease Center located at the University of Texas Southwestern Medical Center, also serves as one of the National Institute on Aging's 28 Alzheimer's Disease Centers (ADCs) across the U.S. In this capacity, the Center at UT Southwestern receives extensive federal funding for AD research.²⁷

Figure 4. Texas Alzheimer's Research and Care Consortium (TARCC) Funding

Biennium	Funding Level (GR)	Major Uses of Funding
FY 06-07	\$2 million	Initial recruitment of research volunteers for Data Bank
FY 08-09	\$3.9 million	Recruitment and data collection from 800 additional research volunteers (500 with AD diagnosis, 300 control subjects); Annual data collection from existing volunteers
FY 10-11	\$6.5 million	Recruitment and data collection from additional volunteers, including 500 Hispanic volunteers (research focusing on AD in the Hispanic population is lacking nationally); Annual data collection from existing volunteers
FY 12-13	\$5.23 million	Recruitment of 125 volunteers with a diagnosis of Mild Cognitive Impairment (MCI), which is a risk factor for AD; Annual data collection from existing volunteers

- *Ongoing Funding for the Consortium:* In the five-year strategic state plan, and in testimony presented before the Joint Interim Committee to Study Alzheimer's Disease, funding is frequently mentioned as the most important aspect to advancing AD research.²⁸ Maintaining a consistent funding source is important to ensure that the Texas AD Data Bank can be maintained and built upon in order to track disease progression over the years, advance our understanding of the causes of AD, and eventually lead to better treatments. Extensive AD research is being conducted at universities and medical institutions throughout the state that are not currently members of the Consortium. Increased funding for the Consortium would allow for additional Texas institutions where AD research is being conducted to be added to the Consortium. This would increase collaboration among Consortium institution researchers and those that are currently conducting important work outside of the Consortium.

To maximize total funding for AD research, the Texas Council and the Consortium should aggressively pursue external sources of funding to supplement state General Revenue. In an effort to pursue external funding, the Council and the Consortium should create written materials that clearly and concisely highlight the many accomplishments of the Consortium since its inception, particularly the large size of the Texas AD database, the large representation of Hispanic subjects in the database (an underserved area within AD research nationally), and the longitudinal nature of the research conducted using the Data Base. The Council and Consortium members should use this document to solicit funding from a variety of federal, private, and non-profit sources.

Potential Funding Sources:

- *National Institutes of Health:* The National Institutes of Health (NIH) funds a significant amount of AD research annually. In FY 2012, total NIH funding for AD research totaled \$498 million.²⁹
- *National Alzheimer's Project Act:* The National Alzheimer's Project Act (NAPA) calls for the creation of a National Plan to combat Alzheimer's Disease. The formation of this plan is currently underway. The Administration's FY 2013 budget calls for \$80 million for AD as part of the Prevention and Public Health Fund allocation. Part of this funding would be used to develop and implement the National Plan, and part of it would be used to support AD research. If approved by Congress, this funding could offer a means of financing some of the research-related goals and strategies contained in the Texas State Plan.³⁰
- *Private and Non-Profit Foundations:* There are several local and state-wide non-profit organizations and private foundations in Texas that have a profound ability to raise funds. These foundations could assist in supplementing state funding for AD research.

Services Available to AD and Dementia Patients

Although an individual with AD would not qualify for any state or federal government programs based solely on their AD diagnosis, these individuals may access services and supports through a variety of government programs depending on their age and their income resources and functional eligibility. These services and supports are offered through Medicaid, Medicare, other government programs, and non-profit organizations.

Medicaid Services

Individuals with AD may access acute and long-term care services in the Medicaid program, depending on their income level, age, and functional ability.

- Acute Care: Individuals who fall below a specified income level and meet other program requirements, such as resources and residency, are eligible to receive Medicaid acute care services. These services include primary and specialty physician care, inpatient and outpatient hospital services, prescription drug coverage, lab and X-ray services.
- Long-Term Care: Individuals with AD who fall below a specified income level and meet other program requirements, such as resources, residency, and medical necessity, are eligible to receive Medicaid long term care services and supports. These services and supports include home and community-based services such as adult day care and personal attendant care, nursing facility services, hospice care, and services furnished under the Program of All-Inclusive Care for the Elderly (PACE). The PACE program is a federal demonstration project that provides community-based services to individuals who are 55 or older, qualify for placement in a nursing facility through Medicare or Medicaid, are able to live safely in the community, and live in the El Paso, Amarillo, or Lubbock service areas that are currently supported under the program. Under the PACE model, individuals receive services at an adult day care center. Services include inpatient and outpatient medical care, specialty services (e.g., dentistry, podiatry), social services, in-home care, meals, transportation, and housing assistance.³¹

Long-term care services are also available through Medicaid waivers. All waivers provide enrollees with personal attendant services, nursing services, professional therapy services, dental care, adaptive aids, and minor home modifications. Different waivers may offer additional services such as home-delivered meals and transitional assistance to move from a nursing facility to community-based care.³²

Medicare Services

All individuals 65 or older are eligible for the federally-funded Medicare program, regardless of income or functional abilities. Since the majority of individuals with AD are 65 or older, the majority of healthcare services for AD are paid for through Medicare. Medicare enrollees have access to acute care services and long-term care services and supports.

- Acute Care: Medicare acute care services include primary and specialty physician services, inpatient and outpatient hospital stays, preventative services, durable medical equipment, and prescription drug coverage.
- Long-Term Care: Although long-term care services are generally not covered under the Medicare program, Medicare Hospital Insurance (Medicare Part A) covers a portion of the cost of the first 100 days of a stay in a skilled nursing facility, hospice care, and some home health care services prescribed for a limited period of time.³³

In-Home and Family Supports

The state provides General Revenue-funded support services to Medicaid-eligible individuals with disabilities who reside in their communities and who need support beyond Medicaid services but do not meet the eligibility requirements necessary to enroll in waivers. These services, known as In-Home and Family Supports, include attendant care, home health services, medical and therapeutic services related to the individual's disability, transportation services, purchase or lease of special equipment or home modifications, and respite care. There is no income limit to receive services, but there is a sliding scale fee for those with incomes over 105% of the Texas median income. The level of services each individual receives are based on a biannual medical needs assessment, with a limit of \$1200 worth of services annually.³⁴

Community-Based Government Agency Services:

Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs) offer services and supports to aging Texans, including those with AD and other types of dementia, depending on their age and other eligibility criteria.

- Area Agencies on Aging (AAAs): A network of 28 AAAs throughout the state provide direct services to seniors and their caregivers and connect them to services provided in the community.³⁵ AAA services are available to individuals 60 or older, and are targeted to those with the greatest economic and social need, with particular attention to low-income individuals, minorities, and people residing in rural areas. Services include information and referral to services, benefits counseling and legal assistance, care coordination, caregiver support services, in-home support services and nutrition services.³⁶
- Aging and Disability Resources Centers (ADRCs): Fourteen ADRCs located throughout Texas serve as a direct access point to long-term care services for individuals with AD and dementia³⁷ ADRCs partner with DADS local offices, AAAs, Medicaid eligibility offices, hospital discharge planners, independent living centers, Local Mental Health Authorities (LMHAs), and other community-based organizations to connect elderly individuals, including those with AD, to nursing facility care, assisted living facility care, and other long-term care services and supports.³⁸ In addition to providing assistance in navigating the long-term care system, ADRCs also offer assistance in determining individuals' eligibility for state and federal programs that provide medical and other services.

Integrating Clinical Care with Research: Just as important as the services and supports available to individuals with AD are the settings in which they receive care. Patients suffering from AD are most effectively served in settings where their clinical needs (such as primary care, specialty care, support services, and memory loss assessments) are incorporated with research facilities that allow them to participate in clinical trials. In a research-only setting, patients can participate in clinical trials but do not receive ongoing medical attention and clinical care. In clinical-only settings, patients cannot access the latest in clinical trials and their experiences aren't being captured in order to advance research. Currently, the only facility in Texas that integrates clinical patient care with research is the Baylor College of Medicine's Alzheimer's Disease and Memory Disorder Center in Houston.³⁹ This setting gives patients more specialized care than

either primary or specialty care settings, and allows patients easy access to participate in clinical trials. Any attempts to secure additional funding for research purposes should consider ways to incorporate clinical care into research settings.

Reimbursement for care of AD patients: The effective treatment and management of AD requires collaboration between a variety of medical and behavioral specialists such as primary care providers, nurses, neurologists, physical therapists, social workers, and mental health experts. Often these groups of providers are co-located and spend significant time consulting with each other to determine the best course of treatment for a patient. Under Medicare, the primary payer source for clinical treatment and management of AD, providers are reimbursed based on the time spent with each patient, without consideration for the additional time that providers often spend consulting with each other to develop appropriate treatment plans for each patient. Some stakeholders believe that there should be special, enhanced Medicare reimbursement rates for the treatment of AD patients to account for multi-provider patient consultations and to ensure that the costs of treating AD patients are covered by reimbursement rates. Since Medicaid is an entirely federally-funded program, the state does not set reimbursement rates.

Services Available to Caregivers

Caregivers often bear the burden of performing essential daily tasks for their loved ones with AD, as well as managing the individual's legal and financial affairs, and finding and accessing supportive services. Due to the stress associated with providing these services and the need to manage these demands with other family member's needs and in some cases, full or part time employment, many caregivers seek help in the form of respite care, financial support, and other services such as support groups and educational materials.

Respite Care: Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. The Take Time Texas website, operated by DADS, includes a searchable database of respite services available to caregivers across the state.⁴⁰ These services are available through all Medicaid waivers and through the Lifespan Respite Program for those not eligible for Medicaid.⁴¹

- Lifespan Respite Program: Created by House Bill 802 (Davis, 81R) in 2009 to identify and serve caregivers who do not qualify for state respite services, the Lifespan Respite Program is currently being implemented as a six-site pilot at five ARDCs and one AAA. As part of the program, these entities are charged with expanding the availability of and access to respite services. Three of the ADRCs that serve as Lifespan Respite Program pilot sites are also required to create a formal media and marketing campaign to increase awareness of these services and replicate two evidence-based models to educate and support caregivers.⁴²

Financial Support for Caregivers: Caregivers may also receive payment for their services through certain waivers:

- Family members (other than spouses) may be paid as personal attendants through the Community-Based Alternatives (CBA) waiver;

- Family members (other than spouses) may be hired to provide supported home living services through the Home and Community Based Services (HCS) waiver, as long as they do not live in the same household as the individual receiving HCS waiver services.⁴³

Non-profit Organizations: Non-profit organizations such as the Alzheimer's Association and the Alzheimer's Foundation of America offer support and assistance to caregivers.

- Alzheimer's Association: The Alzheimer's Association offers many services and supports through the six local chapters of the Association that operate thirteen offices throughout the state, including:
 - An online AD and Dementia Caregivers Center, which offers caregiver training and education through online courses and workshops, brochures and newsletters, and books and DVDs;
 - A 24-hour multi-language help-line for caregivers;
 - Local support and bereavement groups for caregivers; and
 - The Community Resources Finder, a comprehensive listing of Alzheimer's resources and community programs and services such as respite care, assisted living facilities, nursing facilities, home health care, and listings for local government entities that provide services such as AAAs and ADRCs.
- Alzheimer's Foundation of America (AFA): The AFA offers the following services to caregivers through their website and through sixteen local entities throughout Texas, including Alzheimer's Alliance chapters, adult day cares, assisted living facilities, home health providers, and faith-based organizations:
 - A toll-free hotline staffed by social workers who refer family members and caregivers to local support services and answer questions about caregiving and other aspects of AD;
 - Conferences and workshops for caregivers and AD professionals that cover AD diagnosis and medical breakthroughs, financial and legal issues, and caregiving strategies;
 - Support and bereavement groups for caregivers; and
 - Respite care programs and respite care grants to families who cannot afford the cost of respite care or adult day care services.⁴⁴

Improving Accessibility of AD research findings to families and caregivers: Testimony presented to the Joint Interim Committee to Study Alzheimer's Disease emphasized the need to consolidate and repackage information at a centralized entity to make the latest AD news and research findings more accessible to family members and caregivers. Some stakeholders have suggested that this be accomplished through the creation of a state-operated clearinghouse to process, summarize, and disseminate all AD-related information to family members, caregivers, and those who have AD or are at risk of developing it. Ensuring that families, caregivers, and patients have comprehensive, accurate information regarding the latest news and developments in AD research and care is a task most appropriately placed with existing local entities such as AAAs, Alzheimer's Associations, and ADRCs. Families of individuals with AD are already connected to and familiar with these types of organizations. Efforts to create a clearinghouse of AD information should be undertaken by an established Alzheimer's-related organization with a

state-wide presence, rather than a state agency that may not be well-known to families and caregivers of individuals with AD.

Section III: Conclusion

AD takes a significant toll on individuals who suffer with the disease as well their family members and caregivers. The impact of AD in Texas is reflected in the significant economic and healthcare costs of the disease. The Texas Legislature has developed resources to support individuals with AD and their families and caregivers, including the Texas Council on Alzheimer's Disease and Related Disorders. Support services are also provided by local and national non-profit organizations, who work to connect families and individuals with AD to services and supports in their communities. In addition to providing support to individuals with AD and their families, the Legislature has also continued to prioritize AD research and the collaboration of AD researchers through the Texas Alzheimer's Research and Care Consortium. There are significant opportunities for external funding sources for AD research, and these opportunities should be fully explored in order to supplement existing state resources.

Section IV: Recommendations

- 1. Increase AD research funding by increasing state resources for the TARCC as the fiscal climate in the 83rd Legislative session allows. As additional resources allow, TARCC should seek to add Texas institutions to their membership.**
- 2. Encourage the TARCC and the Texas Council on Alzheimer's Disease and Related Disorders to aggressively pursue all funding sources to support research and implementation of the strategic five-year state plan. This should include federal funds available through the National Institutes of Health (NIH) and the Prevention and Public Health Fund, as well as funds available through private and non-profit entities.**
- 3. In order to solicit external funding, the TARCC should develop and circulate written and online materials that clearly outline their significant accomplishments to date, including the Texas AD Data Bank, the large representation of Hispanic research subjects in the Data Bank, the longitudinal nature of the Data Bank, and the ongoing development of a blood test to predict the development of AD.**
- 4. An established AD-related organization with a state-wide presence should create and operate a clearinghouse for all news stories related to developments in AD research and treatment in order to summarize and disseminate this information to those at risk and their caregivers.**

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- ¹ Texas Council on Alzheimer's Disease and Related Disorders, 2012 Biennial Report, p. 3.
- ² 2012 Alzheimer's Disease Facts and Figures, Volume 8, Issue 2, Alzheimer's Association, p. 24.
- ³ *Id.* at p. 21.
- ⁴ Presentation by Dr. Valory Pavlik, Baylor College of Medicine, "Alzheimer's Disease Research: Goals, Strategies, Resources", May 17, 2012, p. 2.
- ⁵ *Id.*
- ⁶ 2012 Alzheimer's Disease Facts and Figures, Volume 8, Issue 2, Alzheimer's Association, p. 5.
- ⁷ *Id.* at p. 7.
- ⁸ *Supra* note 6 at p.5.
- ⁹ *Supra* note 6 at p.40.
- ¹⁰ Dr. David Lakey, Texas Department of State Health Services, Presentation to the Senate Committee on Health and Human Services, February 28, 2012, p.7.
- ¹¹ Enrollment data provided by Department of Aging and Disability Services, based on August 2011 data.
- ¹² Based on Department of Aging and Disability Services monthly claims enrollment and cost data from August 2011.
- ¹³ *Id.*
- ¹⁴ Weighted average monthly cost of nursing facility and CBA waiver programs enrollees with an AD diagnosis.
- ¹⁵ 2012 Alzheimer's Disease Facts and Figures, Volume 8, Issue 2, Alzheimer's Association, p. 37.
- ¹⁶ Based on data from Texas Department of State Health Services Alzheimer's Disease Program.
- ¹⁷ 2012 Alzheimer's Disease Facts and Figures, Volume 8, Issue 2, Alzheimer's Association, p. 37.
- ¹⁸ House Bill 1066, Evans, 70R
- ¹⁹ Texas Council on Alzheimer's Disease and Related Disorders, 2010 Biennial Report, p. 10.
- ²⁰ House Bill 1066, Evans, 70th Regular Session
- ²¹ A Comprehensive Plan for Addressing the Burden of Alzheimer's Disease in Texas: 2010-2015 Texas State Plan on Alzheimer's Disease
- ²² *Id.* at p.12.
- ²³ House Bill 1504, 76th Regular Session, 1999 (Goolsby/Harris).
- ²⁴ *Id.* at p.12.
- ²⁵ Information obtained from http://www.txalzresearch.org/index.php?option=com_content&view=article&id=45&Itemid=59 on June 14, 2012.
- ²⁶ *Id.* at p. 13.
- ²⁷ Information obtained from <http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers#UTex> on July 5, 2012.
- ²⁸ *Id.* at p. 15
- ²⁹ Information obtained from http://report.nih.gov/categorical_spending.aspx#legend4 on June 13, 2012.
- ³⁰ U.S. Department of Health And Human Services Press Release: "Obama administration presents national plan to fight Alzheimer's disease," May 15, 2012.
- ³¹ Information obtained from <http://www.dads.state.tx.us/services/faqs-fact/pace.html> on June 12, 2012.
- ³² Information provided by DADS via email dated June 11, 2012.
- ³³ "Medicare and You", Centers for Medicare and Medicaid Services. Available at: <http://www.medicare.gov/publications/pubs/pdf/10050.pdf>. Accessed on June 7, 2012.
- ³⁴ Information received from DADS via email dated June 11, 2012.
- ³⁵ *Id.* See also DADS Senate HHS Presentation, slide 4. Family members and other caregivers may receive information and services on behalf of the senior for whom they are providing care.
- ³⁶ See "Area Agencies on Aging," Texas Department of Aging and Disability Services. Available online at <http://www.dads.state.tx.us/providers/AAA/index.html> (Last accessed November 10, 2010). For additional information about what each of these services entail, see "Area Agencies on Aging Covered Services." Available online at <http://www.dads.state.tx.us/services/faqs-fact/aaa.html> (Last accessed November 10, 2010). See also DADS Access and Intake Booklet, pp. 66–77.
- ³⁷ DADS Presentation to the Joint Interim Committee on Alzheimer's Disease, February 28, 2012, slide 4.
- ³⁸ "ADRCs rely on partnerships," Texas Department of Aging and Disability Services. Available online at http://www.dads.state.tx.us/news_info/improvingaccess/adrc/partnerships.html
- ³⁹ Information based on visit to Baylor College of Medicine's Alzheimer's Disease and Memory Disorder Center, May 19, 2012.

⁴⁰ Jon Weizenbaum, Texas Department of Aging and Disability Services, Presentation to the Senate Committee on Health and Human Services, February 28, 2012

⁴¹ *Id.* at slide 7.

⁴² *Id.* at slide 8.

⁴³ "Attendant Services in 1915c Medicaid waiver: Personal Assistance Services (PAS), Respite, Habilitation and Supported Home Living", Provided by DADS on June 8, 2012.

⁴⁴ Information obtained from www.alzfd.org on July 5, 2012.