TEXAS LIFESPAN RESPITE CARE PROGRAM

Report to the Texas Legislature

As Required by H.B. 802, 81st Legislature, Regular Session 2009

Submitted to Office of the Governor and Legislative Budget Board

by Texas Health and Human Services Commission in coordination with the Texas Department of Aging and Disability Services

November 1, 2010
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Introduction

H. B. 802, 81st Legislature, Regular Session, 2009 requires the Health and Human Services Commission (HHSC) in consultation with the Department of Aging and Disability Services (DADS) to develop a report on the implementation of H.B. 802, related to the implementation of the lifespan respite care program. The 2010-11 General Appropriations Act (Article IX, Part 17, Section 17.38, S.B. 1, 81st Legislature, Regular Session, 2009) appropriated $1 million to DADS to fund, at a minimum, three community organizations for the expansion of respite services for caregivers of individuals of any age with any chronic health condition(s) and/or any disability, who are not eligible for respite services through other programs.

As a result, the Texas Lifespan Respite Care Program (LRCP) was created in 2009. The objectives of LRCP include: (1) selecting three community-based sites to provide respite services to caregivers who are not eligible for respite services through other programs; (2) creating a respite coordination center; (3) increasing the availability of respite services; (4) implementing a caregiver awareness campaign; and (5) developing best practices for respite care providers.

Along with general revenue appropriated to DADS for the 2010-11 biennium to implement H.B. 802, federal grant funds were secured to support a respite coordination center. All together, funding for the Texas LRCP totals $1.3 million.

This report is required to be submitted to the Office of the Governor and the Legislative Budget Board (LBB) by November 1, 2010, and must include an evaluation of the effect of the Texas Lifespan Respite Care Program on: (1) access to respite services by primary caregivers of persons with chronic serious health conditions or disabilities; and (2) Medicaid expenditures for long-term services provided in institutional care settings. Discussion regarding the impact of LRCP on caregivers can be found in the section below titled, Effect of LRCP on Access to Respite Services by Caregivers and in Appendix B, Lifespan Respite Care Program, Local Contractors: Overview and Progress to Date. Discussion regarding the impact of LRCP on Medicaid expenditures can be found in the section below titled, Effect of LRCP on Medicaid Spending.

Background

Profile of Caregivers in Texas

Informal caregivers, including relatives and friends who provide unpaid care to older individuals and persons with disabilities, are considered the backbone of the long-term care system. In Texas, there are approximately 655,000 older persons and persons of all ages with disabilities...
who need help with daily activities that are at or below 220 percent of the federal poverty level, or have monthly incomes below 300 percent of the monthly income limit for Supplemental Security Income. This does not include the unknown numbers of Texans who live above these thresholds yet depend on informal caregivers on a daily basis. Identifying and meeting the needs of the estimated 2.7 million caregivers in Texas who care for older persons and persons with disabilities often determines whether the individuals needing care can remain at home, or if they must enter an institutional care setting.

As is common throughout the United States, many Texans are unprepared to assume the role of a caregiver when the time comes. Although the state mirrors the nation in the demographic profile of caregivers, the issues affecting them affect caregivers of all types in Texas, including grandparents caring for children, biological, adoptive and foster parents caring for children with special needs, and individuals caring for adults with cognitive and physical impairments and/or chronic conditions.

Of particular concern in Texas is the difficult-to-reach population residing in the state’s vast rural areas. Along with the rural problems of provider shortages, lack of transportation and difficulty in accessing services, rural families are often separated from their extended family and are reluctant to take advantage of agency-based services because of the stigma they associate with them. Another concern in Texas is the large, diverse population of ethnic and racial groups residing along the Texas border and in metropolitan areas. Studies have repeatedly pointed to the reluctance of individuals in these groups, particularly Hispanics and Asians, to reach outside their family and request assistance when they need help with services and supports.

Need for Coordinated and Expanded Respite Care Services in Texas

Respite services are available throughout Texas and are funded through a variety of sources, including state-administered programs such as the Older Americans Act (OAA), Title III, Medicaid, Social Services Block Grant (Title XX), General Revenue Fund, and through other state agencies, such as the Texas Department of Family and Protective Services. Some respite services are also available at the local level through faith-based organizations and local chapters of advocacy organizations serving specific disability populations (e.g., the United Cerebral Palsy of Texas).

While the National Family Caregiver Support Program operating in area agencies on aging statewide, and funded under OAA Title III-E, has made notable inroads in the past few years connecting certain caregivers to services, the system overall remains fragmented, disparately proportioned, and lacks formal methods for coordination across its various components. The availability of respite options also remains insufficient. This is particularly evident in the state’s rural areas and is also apparent by the high number of individuals on the interest lists for some Medicaid waiver programs, such as individuals awaiting enrollment in the Community-Based

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2 Texas Legislative Budget Board, Texas State Government Effectiveness and Efficiency, January 2009.
Alternatives program, the Medically Dependent Children Program and the Home and Community-Based Services program, all of which include respite care in their array of services.

**Implementation of the Texas Lifespan Respite Care Program**

In June 2009, Governor Rick Perry signed two pieces of legislation aimed at identifying caregivers and improving the delivery of caregiver support services in Texas: S.B. 271 (81st Legislature, Regular Session, 2009) relating to informal caregiver support services and awareness, and H.B. 802, relating to the appropriation of $1 million to provide respite services for caregivers of individuals of any age with any chronic condition health condition(s) and/or any disability who are not eligible for respite services through other programs. Both laws became effective on September 1, 2009.

As a result of extensive input in recent years from numerous advocates, stakeholders and state leaders regarding the needs of caregivers, Texas was already well-positioned to implement the LRCP. In fact, DADS had several significant advantages at its disposal to help ensure such a program would be successful, including a close coordination with the Texas Respite Coalition, the establishment of a statewide respite coordination center, and a continuing commitment to the expansion of Aging and Disability Resource Centers (ADRCs).

**Texas Respite Coalition**

In 2009, DADS entered into a memorandum of agreement with the Texas Respite Coalition, whose members have pledged to assist DADS by: (1) providing input on the barriers to respite care in Texas; (2) participating in special inventory and program evaluation activities; and (3) participating in and coordinating with the activities of a newly created statewide coordination center. The Texas Respite Coalition has more than forty member agencies and organizations, and is broadly represented by caregivers of all types who themselves are caring for individuals of various ages with disabilities and chronic health conditions (see Appendix A). Today, the Texas Respite Coalition is having a notable impact in its ability to disseminate key program information to numerous providers and advocates of respite services, and it continues to be supportive of DADS efforts to coordinate the accessibility and availability of respite care for caregivers.

**Texas Respite Coordination Center**

In 2009, DADS actively sought and received federal grant funding in the amount of $200,000 from the Administration on Aging (AoA) to build upon the caregiver awareness activities outlined in H.B. 802 and to further improve the coordination and availability of respite services. DADS proposed to enhance these efforts through the creation of the Texas Respite Coordination Center (TRCC).

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6 The Lifespan Respite Care Act of 2006 (Public Law 109-716) requires that upon grant funds received from AoA, states must work in partnership with statewide respite coalitions to enhance and expand the availability of respite services in the state.
In 2010, DADS contracted with the Texas Association of Regional Councils to serve as the TRCC. The mission of the TRCC is to enhance and expand the coordination and availability of respite services in the state by (1) supporting the respite coordination and outreach efforts of the Texas Respite Coalition, Aging and Disability Resource Centers and the local LRCP contractors; (2) compiling and annually updating a Texas Inventory of Respite Services; (3) conducting respite forums across the state; (4) developing media kits and outreach materials aimed at caregivers; and (5) developing training and best practice tools for providers of respite services.7

Since its establishment in May 2010, the TRCC has been in the planning, recruitment and development stages of collaboration with grant stakeholders and partners, and has begun compiling the Texas Inventory of Respite Services. In August 2010, implementing a strategy to meet an education and outreach component required in its contract with DADS, the TRCC subcontracted with a local marketing firm to assist in the design and creation of outreach materials, as well as the development of caregiver “messages” for various caregiver population groups.8 Finally, plans are underway for the TRCC to hold a series of five respite forums across the state, the first of which will take place in Waco on November 17, 2010.

Aging and Disability Resource Centers

Since 2005, with assistance from AoA and the Centers for Medicare and Medicaid Services, and using administrative funding allocated under the OAA, DADS has established nine ADRCs in Texas, with plans to fund two more in fiscal year 2011.9 ADRCs serve as a “no wrong door” and work to implement innovative models for improving access to long-term services and supports for individuals of all ages and disabilities. Within each ADRC, caregiver support coordinators and system navigators are available to assist caregivers in effectively planning, arranging and coordinating services to meet the identified needs of the caregiver. The nine ADRCs currently in operation are located in:

- Bexar County (San Antonio)
- Central Texas (covering Bell, Coryell, Hamilton, Lampasas, and Milam counties)
- Tarrant County (Fort Worth)
- Gulf Coast (serving Harris, Austin, Brazoria, Chambers, Colorado, Fort Bend, Galveston, Liberty, Matagorda, Montgomery, Walker, Waller and Wharton counties),
- Lubbock County (Lubbock)
- East Texas (serving Gregg, Harrison, Marion, Panola, Rusk and Upshur counties)
- North Central Texas (serving Collin, Denton, Hood, and Somervell counties)
- Dallas County (Dallas)
- El Paso and West Texas (El Paso, Hudspeth, Culberson, Jeff Davis, Brewster, and Presidio counties).

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7 The resources and outreach materials developed by the TRCC will be used in meeting the public awareness requirements of S.B. 271 as well.
8 TRCC Quarterly Progress Report submitted by TARC to DADS, August 31, 2010.
9 DADS plans to establish a total of 20 ADRCs by the year 2020.
Contracts with Local Communities to Expand the Availability of Respite Services

Helping caregivers navigate the system of respite services is an essential activity of the ADRCs and they are an important catalyst for making respite services more easily accessible throughout the state. Since ADRCs already serve individuals of all ages and disabilities, DADS opted to fulfill the requirement in H.B. 802 to contract with at least three local community organizations to expand the availability of, and facilitate access to, respite services by giving preference to applications for funding submitted by any of its ADRCs. Although any local entity was invited to apply for the funds, DADS required successful applicants to have the capacity to serve caregivers caring for individuals of any age, disability and chronic health condition. DADS also required applicants to have experience in providing caregivers information about respite care and connecting them to services, building partnerships and conducting local public awareness activities.

In August 2010, three communities were selected: the ADRCs of Tarrant County and Central Texas, and the Area Agency on Aging of the Capital Area. These organizations were selected for their extensive experience in providing caregivers information about respite care and connecting them to services. For the LRCP, the contractors are placing special emphasis reaching isolated caregivers living in very rural areas and where applicable, targeting and conducting culturally sensitive outreach and awareness activities to Hispanic and Asian caregivers. The contractors also have the responsibility for assisting caregivers who are not eligible for respite services through other programs.

Additionally, the new contractors are expected to expand the availability of respite services in their communities, including new and emergency respite services. They are encouraged to explore and develop whenever possible the use of volunteer respite programs. The contractors must also provide caregivers the option of receiving respite services through the use of vouchers, using the procedures already prescribed by DADS and outlined in 40 Texas Administrative Code (TAC), Part I, Chapter 85, Subchapter D, §85.310. Wherever feasible and appropriate, the new contractors must use the consumer-directed services model, as prescribed in 40 TAC, Part I, Chapter 41, Subchapter A, §41.01. Finally, the local partners are expected to work closely with the TRCC and the Texas Respite Coalition in raising caregivers’ awareness about the availability and benefits of respite services. The local contractors will accomplish this by contributing to the TRCC’s development of how-to guidelines and resources (including best practices for recruiting respite care workers and volunteers) for other areas of the state seeking to expand respite services in their own communities.

All three contractors have begun working on vendor agreements and conducting meetings to introduce the vendors and other partners to the details of the program, intake procedures and how respite services will be authorized and delivered. Designated project coordinators either have been identified or are being hired and marketing plans have been initiated, which range from printing brochures and materials in English, Vietnamese and Spanish to co-hosting a local caregiver conference.

Appendix B of this report provides additional detail regarding each local contractor’s programs, goals, and progress to date.
Effect of LRCP on Access to Respite Services by Caregivers

In pursuing the objectives outlined for the Texas Lifespan Respite Care Program, DADS, the TRCC, the Texas Respite Coalition and the local contractors expect to achieve two significant outcomes: (1) caregivers in Texas will have a greater knowledge about, and access to, a wider array of respite care options; and, (2) Texas will have a statewide lifespan respite care system that has greater capacity and is more comprehensively coordinated across service systems.

To test its effectiveness in accomplishing these outcomes, DADS has entered into an interagency agreement with HHSC, whose evaluation staff will use both qualitative and quantitative methods to assess key performance indicators. For example, throughout the project period, HHSC will determine whether DADS is effective in implementing its Lifespan Respite Care program by annually examining the program’s processes and work plan accomplishments. Specifically, HHSC will analyze indicators such as the extent to which the program’s actual implementation matches its original program design, and variations, unanticipated outcomes and lessons learned.

Beginning in fiscal year 2011, and working from the Texas Inventory of Respite Services, HHSC will periodically sample provider agencies of respite services, and using open-ended interviews, determine the extent to which respite services are better coordinated throughout the state. In fiscal years 2011-12 of the initiative, and using information from the initial and updated Texas Inventory of Respite Services, as well as sample data provided by the ADRCs and agencies and organizations identified by the Texas Respite Coalition, HHSC will determine whether or not respite services have increased in capacity in the state, including where in Texas they have increased. This analysis will include the identification of new respite services made available through the H.B. 802 funds, as well as the discovery of existing services and programs that had not been previously known or identified as respite care resources.

Throughout fiscal year 2012, identifying caregivers through the assistance of the Texas Respite Coalition, HHSC will conduct a statistically valid survey of caregivers across all agencies and disability populations and poll them on the various indicators described above, regarding their role as caregivers and their understanding of available respite options.

Appendix B of this report contains more detail about how the local LRCP contractors expect to enhance the provision of respite services to caregivers in their communities.

Effect of LRCP on Medicaid Spending

Assisting Texans in preparing for and sustaining their roles as caregivers can have a positive impact not only on the individuals receiving care, but also by helping them avoid long-term services and supports costs that might otherwise be shifted to Medicaid. It is estimated caregivers save the state $3.2 billion to $12.6 billion in Medicaid institutional spending annually.¹⁰

¹⁰ Texas Legislative Budget Board, Texas State Government Effectiveness and Efficiency, January 2009.
Beyond this estimate, however, it is not possible to determine the specific impact of LRCP on the cost of services for those individuals who are at risk of being placed in a nursing facility. Many factors contribute to the actual level of this risk, including: (1) whether or not the individual lives alone and whether or not a caregiver is available; (2) the length of an illness and/or hospitalization; (3) the extent to which assistance with activities of daily living is needed; (4) the extent to which there is an impaired level of consciousness; (5) education level; and (6) a vulnerability to falling.

Moreover, many factors can contribute to the expense of long-term services and supports, including changing demographics, the local and state economy and the availability of service providers and other resources in an individual’s community. Finally, while it is too early to determine how caregivers served specifically by local LRCP contractors will impact the total number of individuals admitted to city, county, or state institutions across Texas, HHSC and DADS will be examining this effect throughout fiscal years 2011 and 2012. DADS is also closely monitoring the progress of its Community Living Program (described below) which is already indicating that armed with enough awareness, education, training and resources, caregivers can often delay and sometimes even avoid nursing facility placement for their loved ones.

**Other Initiatives Related to Caregivers and Respite Care Services**

Recognizing and meeting the needs of Texas caregivers has been a priority of DADS, as evidenced by the 2001 implementation of the National Family Caregiver Support Program (aimed at older consumers), the respite services available through the Medicaid waiver programs, and numerous other services and supports that are not labeled “respite,” yet have the net benefit of providing relief for caregivers. Throughout fiscal year 2010, the agency has increased this focus even further for all caregiver groups by implementing a number of other initiatives related to the role of caregiving and the provision of services to support them, and these activities are summarized below.

**Senate Bill 271**

S.B. 271 incorporates the 2009 recommendations of the LBB relating to strengthening informal caregiver support services, including: (1) raising public awareness about caregiving and available support services; (2) implementing a caregiver status form into the existing Medicaid functional eligibility determination process; (3) standardizing a caregiver assessment and protocol for caregivers accessing services through AAAs; and (4) analyzing the data collected from the caregiver status form and caregiver assessment form.

The LBB recommendations and ensuing passage of S.B. 271 were supported in part by a report published by DADS in October 2009 titled *Informal Care in Texas: Aging Family Caregivers and Their Need for Services and Support*. Utilizing the results of stakeholder focus groups held in 2004, the report specifically focused on the aging Texas population of family caregivers and described the role these individuals play in ensuring the individuals under their care are able to remain in their homes. The report concludes:

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11 Ibid.
Informal or family caregivers, whether a grandparent caring for a grandchild or someone caring for an older family member or friend, have identifiable needs for services and support. When these needs are met, the caregiver is able to continue to provide informal care for a longer period of time. The longer that care is provided by informal caregivers, the less impact there is on public funds and public programs for formal care through both community-based and institutionally-based settings. Stakeholders and experts agree that budgetary constraints, along with the rising cost of providing formal care and services to individuals could be addressed by further recognition of the value of informal caregivers and the need for supportive services so they can and will continue to provide quality care for their loved ones in the community.”

Raising Public Awareness

To promote AAAs as the resource for caregivers, DADS is developing a coordinated, statewide multimedia marketing campaign kit for use by AAAs. The kit will be completed in spring 2011 and contain sample brochures, bookmarks, flyers, posters, news articles, sample public service announcements for radio and television, etc. These materials will also be uniform, available in electronic media formats and easily replicable. Use of these materials is expected to increase public awareness of the services and supports available to caregivers through AAAs.

In addition, new 2010 federal grant funding for ADRCs included a requirement for ADRCs to focus on outreach to “critical pathways,” which includes healthcare professionals and hospital and nursing facility staff. ADRCs must work to establish partnerships within these pathways to raise professionals’ awareness of the existence of ADRCs, as well as the availability of system navigation and options counseling services, which can be critical resources for caregivers.

Both AAAs and ADRCs provide ongoing education and training to caregivers to help them make decisions and solve problems associated with caregiving. AAAs also routinely disseminate information for informal caregivers, grandparents or relatives caring for children 18 years of age and under; as well as to the public through publications, large group presentations, seminars, health fairs and mass media. ADRCs disseminate information to caregivers through these same outlets, including caregivers of persons with disabilities. Both AAAs and ADRCs utilize their partnerships with local 2-1-1 Area Information Centers to maintain key links to 2-1-1 resource databases and to enhance referrals wherever possible.

Special Outreach Initiatives of ADRCs

ADRCs also employ special outreach and awareness initiatives for caregivers, including:

- the use of electronic messaging (such as “Constant Contact”) for news and resource dissemination to area professionals;
- the creation of a “First Aid Kit” for hospital discharge planners, which provides a compilation of ADRC resources available in the community. The kit allows hospital staff to present patients and their caregivers with an array of choices for transitioning from the hospital back to the community; and
• the provision of education and outreach to specific targeted populations with information about resources and system navigation. These populations include the Korean, Vietnamese, and Indian communities within the Dallas metropolitan area.

Additionally, the Tarrant County ADRC is examining the feasibility of establishing a “mobile” ADRC. A large recreational vehicle (RV) would be modified to house ADRC resources. The system navigation team would then travel in the RV to special events, senior centers, health fairs, etc. to provide access for consumers and caregivers living in areas outside of the current ADRC location.

The Central Texas ADRC has been nationally recognized for its innovations in caregiver awareness and support. In October 2009, the Rosalyn Carter Institute for Caregiving (RCI)\(^{12}\) awarded its Rosalyn Carter Leadership in Caregiving Award to the ADRC and its partner, the Scott & White Healthcare System, for providing a seamless array of support services to caregivers in the Central Texas region. In February 2010, AoA awarded its Changing Lives Award to the Central Texas ADRC for creating and leveraging diverse partnerships to bring evidence-based programming for family caregiver to the community.

**Other Caregiver Awareness Resources Offered by DADS**

DADS is developing a procedure for issuing a caregiver letter and resource list, which will be mailed by the agency’s regional offices to every caregiver identified on the Caregiver Status Questionnaire (discussed below). DADS will expand the list of resources available in its resource guide, *Long-Term Services and Supports, Services for Adults and Children with Medical/Physical Disabilities*, as the TRCC develops more comprehensive caregiver resources.

Finally, in 2011, DADS will produce an annual calendar to provide caregivers and the general public with information and resources on caregiving. The calendar will include facts and resources related to caregiving for each month, toll-free numbers of AAAs and ADRCs and links to a variety of web-based tools and materials. Calendars will be distributed to the ADRCs and the TRCC, and will also be disseminated electronically to the member agencies of the Texas Respite Coalition, who will make the calendar available for download on their respective websites.

**Caregiver Status Questionnaire and Caregiver Assessment**

As required by S.B. 271, DADS developed a Caregiver Status Questionnaire (CSQ) to identify and collect information pertaining to primary informal caregivers. The tool is also used to refer persons who may qualify for services provided through AAAs. The questions in the CSQ are designed to provide DADS with a demographic profile of the caregiver and are not intended to assess the needs of the caregiver. The CSQ will be applied to informal (unpaid) caregivers of new interest list consumers entered into the agency’s automated intake system for the following programs: Community Care for the Aged and Disabled, Community-Based Alternatives and the

\(^{12}\) RCI recognizes innovative partnerships between community agencies and caregiving researchers that bridge the gap between science and practice.
In-Home and Family Support Program (IHFSP)\textsuperscript{13}. The intake system is used to register persons interested in receiving Medicaid services provided through DADS programs, until such time as funding is available to provide actual services. The CSQ will be completed at the time of the intake telephone contact for all new intakes. If the identified caregiver is not available, one additional contact with the caregiver will be attempted. Identification of the caregiver is voluntary by the person who contacts intake staff.

Additionally, as required by S.B. 271, a caregiver assessment was developed to assist in identifying needs and appropriate services for caregivers accessing services through AAAs. Results of the assessment are used to develop an individual plan of care, as appropriate. The assessment will be completed on all caregivers receiving Care Coordination or Caregiver Support Coordination funded through OAA Title III-E.\textsuperscript{14}

In fall 2009, input regarding the CSQ was sought from long-term services and supports regional directors and regional community care intake workers and screeners on its use during the Medicaid functional eligibility determination process, and this feedback was incorporated into the tool. Additionally, a draft of the caregiver assessment form was released to AAA directors across the state for review and comment by their staff and this input was incorporated into the form. Moreover, because both the CSQ and the caregiver assessment contain demographic information vital to developing a profile of caregivers in Texas, any modification to one form requires the same modification to the other.

In January 2010, DADS performed a two-week limited pilot of the CSQ in hard-copy format in selected regional intake offices across the state (regions 2, 6, 7, 8, 9). A total of 134 caregivers participated in the pilot, and results of the pilot were discussed during a debriefing teleconference with regional representatives.

Meanwhile, the caregiver assessment was also tested in selected local AAA pilot sites across the state (AAAs of Concho Valley, Coastal Bend, Deep East Texas, Permian Basin, North Texas, Harris County, Dallas, Panhandle and West Central Texas) between February and March. The results of the pilot, including responses collected from 110 caregivers, were discussed with AAA directors and other staff in a debriefing teleconference. Modifications resulting from comments received during these testing activities were incorporated into the assessment and the CSQ.

Over the ensuing months, staff incorporated the approved versions of the CSQ and the caregiver assessment into DADS’ respective automated data systems. These efforts led to the successful deployment of the CSQ on August 2, 2010, and the successful deployment of the caregiver assessment on August 9, 2010.

\textsuperscript{13} Ten of the 11 regions use DADS’ automated intake system to capture IHFSP.

\textsuperscript{14} “An adult family member, or another individual, who is an informal provider of in-home and community care to an older individual...”, and, “a grandparent or older individual who is a relative caregiver is defined as “a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage, or adoption who is 55 years of age or older and lives with the child, is the primary caregiver, and has a legal relationship to the child, or is raising the child informally”, Older Americans Act, as amended in 2006, 42 U.S.C. §3022.
Data Analysis

Efforts are underway to develop reports from the data collected through both the CSQ and the caregiver assessment, which will enable DADS to extract information for future analysis. One of DADS’ new automated data systems, the State Unit on Aging Programs Uniform Reporting System, was deployed June 2010, and the AAAs are required to enter caregiver assessment information into this new reporting system. DADS will analyze the data collected and reported through this system, as well as its Community Services intake system, prior to submitting the report by December 1, 2012, as required by S.B. 271.

Community Living Program

As previously discussed, DADS is observing notable progress in implementing its Community Living Program, especially with regard to the resources the program offers to caregivers. DADS and its local partners have been working identifying and implementing practices to assist caregivers in helping their care recipients to transition from a hospital stay back to home, especially if the patient is at high risk of being discharged to a nursing facility. With funds received from AoA in 2008, DADS created the CLP in partnership with the Central Texas ADRC and Scott & White Healthcare System to establish a nursing home diversion program for individuals at imminent risk for nursing home placement and Medicaid spend-down. Additionally, in September 2009, DADS was awarded a new two-year grant from AoA to support an additional CLP between DADS and the Tarrant County ADRC.

The CLP uses specialized assessments to create an effective risk profile for the family caregiver. These assessments include indicators associated with family caregiving such as: (1) the need for additional in-home skilled nursing care; (2) the inability to leave the care recipient alone; (3) high levels of stress versus satisfaction; (4) the physical burden assumed, and declining health of, the caregiver; (5) the care recipient’s behavioral problems; and, (6) the desire to institutionalize the patient. Upon identifying a high-risk consumer, staff working as “care transition specialists” use a multi-team transition process pioneered by the University of Colorado Health Science Center, known as the Care Transitions Intervention.

The Care Transitions Intervention is an evidence-based program designed to empower seniors and their caregivers to effectively manage the challenges of changing care settings. Research has shown patients with complex needs requiring care across different health care settings are vulnerable to experiencing serious problems with those care transitions (e.g., hospital to home, hospital to intended short-stay nursing home). Patients and their caregivers are often the only common thread moving across care settings and constitute an important target for an intervention to improve quality of care and prevent nursing home placement.

To address these issues, a care transition specialist leads the patient and caregiver through a care planning process aimed at four pillars of care: (1) medication self-management; (2) maintenance of a patient-centered record, owned and maintained by the patient; (3) scheduling timely follow-ups with health care professionals; and (4) developing and understanding a list of "red flags" that indicate a worsening condition, with instructions about how to respond.
Using these tools and practices, along with the risk profile described above, DADS anticipates a notable reduction in non-constructive individual and family behaviors, such as limited respite support for the caregiver, poor adherence to medical/medication treatments, high levels of caregiver burden and loss of functioning associated with nursing home placement decisions.

In September 2010, DADS received funding from the Affordable Care Act grant through a grant from AoA to expand the Care Transitions Intervention project operated by the Central Texas ADRC and its partner Scott & White Healthcare. This grant will increase patient and caregiver access to the intervention throughout a broader region by working with a second hospital in Central Texas. In addition, a long-term plan is being developed for the statewide dissemination of training to all ADRCs in Texas on the practices and techniques for using the Care Transitions Intervention model.

**Summary**

DADS has worked to strengthen its provision of caregiver support services over the past year, including the development and implementation of the CSQ and the caregiver assessment, expansion of the ADRC initiative, and initiating steps toward promoting awareness of caregiver resources. Additionally, the creation of the TRCC and the Texas Respite Coalition is enabling DADS to advance the provision of services in Texas for all caregivers caring for individuals of any age, disability or chronic health care condition.

The production of the Texas Inventory of Respite Services by the TRCC will be an important tool for increasing public awareness of available caregiver resources. Local AAAs, DADS regional community services intake offices and ADRCs across the state will have access to this inventory, as well as to all materials, tool kits, and best practices being developed by the TRCC. In addition, the establishment of two additional ADRCs by DADS in 2010 will advance the goal of streamlining access to long-term services and supports in Texas and empower individuals and their caregivers to make informed choices about the resources they need.

Finally, over the next 12 months, DADS and the three local LRCP contractors will expand the availability and awareness of respite services within specific geographic areas. These projects will be a key to developing the LRCP and will provide the building blocks for a statewide infrastructure in the delivery of respite services for caregivers.
Appendix A

Memorandum of Agreement Between the
Department of Aging and Disability Services
and the
Texas Respite Coalition
TEXAS LIFESPAN RESPITE CARE PROGRAM:
MEMORANDUM OF AGREEMENT
Texas Department of Aging and Disability Services
Texas Respite Coalition

Background

The Texas Legislature enacted two laws affecting respite care for caregivers in Texas. Senate Bill 271, 81st Legislature, Regular Session, 2009, directs the Texas Department of Aging and Disability Services (DADS) to coordinate public awareness outreach efforts regarding the role of informal caregivers in long-term care. House Bill 802, 81st Legislature, Regular Session appropriated $1,000,000 over the Fiscal Year 2010-2011 biennium and directs DADS to create a lifespan respite services program. Furthermore, DADS intends to apply for $200,000 in grant funds available under the U.S. Administration on Aging (AoA) to enhance and expand the coordination and availability of respite services in Texas.

The agencies and organizations identified in this Agreement are active members of the Texas Respite Coalition (“Coalition”) and are in support of the goal to enhance and expand the coordination and availability of respite services in Texas. Therefore, DADS and the Coalition shall enter into this Memorandum of Agreement, effective on the last signature date noted below.

DADS agrees to:

1. Create a Texas Lifespan Respite Care Program;
2. Pursue federal funding available through AoA to enhance and expand the coordination and availability of respite services across Texas;
3. Use a portion of AoA funds to create a statewide Texas Respite Coordination Center (“Coordination Center”) to: (a) support the Coalition’s efforts; (b) create a “Texas Inventory of Respite Services”, (c) conduct respite forums across the state; (d) develop unified media kits and public messages aimed at caregivers across the state and across disability populations; and (e) develop training and best practice tool kits for providers of respite services;
4. Use a portion of the AoA funds to support a formal evaluation of the effectiveness of the Texas Lifespan Respite Care Program;
5. Provide state level support and direction to both the Coalition and the Coordination Center; and,
6. Administer and award the funds available under House Bill 802 to entities to enhance the coordination and availability of respite services at the local level.

Items three and four above are contingent upon approval of federal grant funds from AoA. In the event AoA funds are not awarded to Texas, item five above is amended to read: “DADS agrees to provide state level support and direction to the Coalition.”
Member agencies of the Texas Respite Coalition agree to:

1. Assist DADS and the Coordination Center in the identification of barriers and best practices for providing and coordinating respite services in Texas;

2. Respond to requests from DADS or the Coordination Center for information about the respite needs of caregivers, or provide an inventory of respite services available through their respective programs;

3. Advise DADS regarding effective methods for expanding the availability of respite services in the state through the administration of funds available under HB 802;

4. Distribute and utilize all media and best practice tool kits, training curricula and other products developed by the Coordination Center to its network of providers and/or caregivers, as appropriate; and,

5. Working with the program evaluator secured by DADS, (a) participate in requests to conduct agency or provider interviews about the coordination and availability of respite services from their perspectives; and (b) encourage consumers’ participation in a survey process regarding caregivers’ needs and the availability of respite services and other resources.

In the event AoA funds are not awarded to Texas, the activities listed in items one and two above are amended to include only DADS and provisions 4 and 5 in this subsection shall be of no force and effect. DADS and the Coalition agree to negotiate in good faith replacement terms as appropriate.

This Agreement is further subject to amendment and expansion upon the creation of the Texas Respite Coordination Center and its duties and responsibilities to the Coalition and DADS.

______________________________________________  ____________________
Official Signatory for the Texas Respite Coalition  Date
Kim Suiter
National Multiple Sclerosis Society, Lone Star Chapter

______________________________________________  ____________________
Gary Jessee  Date
Assistant Commissioner
Access and Intake Division
Texas Department of Aging and Disability Services
The Texas Respite Coalition: Member Agencies and Organizations

*Representative is a Caregiver

AARP Texas
Adult Day Care Association of Texas
*Advocacy, Inc.
*Alzheimer’s Association, Greater Dallas Chapter
Border Alliance of Adult Day Care Centers
DFPS Adult Protective Services & Child Protective Services
Early Childhood Intervention Program (DARS)
Easter Seals, Central Texas—Central Texas Respite Network
Easter Seals, North Texas
EveryChild, Inc.
*Houston Area Respite Center
National Multiple Sclerosis Society, Lone Star Chapter
*Private Providers Association of Texas
Respite Care of San Antonio, Inc.
Texas Association for Home Care
Texas Association of Area Agencies on Aging
*Texas Center for Disability Studies
Texas Community Resource Coordination Groups
Texas Council for Developmental Disabilities
*Texas Council of Community MHMR Centers
Texas Alzheimer’s Disease Program (DSHS)
*Texas Kincare Task Force
Texas Traumatic Brain Injury Advisory Council
*Texas Tech University: Garrison Institute on Aging
The ARC of Greater Houston
The ARC of Texas
*United Cerebral Palsy of Greater Houston
*United Cerebral Palsy of Texas
University of Texas School of Nursing Professor, Representing Self
Appendix B

Lifespan Respite Care Program

Local Contractors: Overview and Progress to Date
Lifespan Respite Care Program  
Local Contractors: Overview and Progress to Date

ADRC of Tarrant County

Contract Amount:  
$350,500

Number Impacted and Cost Per Person Anticipated:  
417 caregivers at an average cost of $1,897 per caregiver.

Overall Goal:  
To increase the availability of and facilitate access to respite care for Tarrant County caregivers of adults with physical disabilities, intellectual and developmental disabilities (IDD), and older adults with Alzheimer’s disease.

Geographical Region:  
The service area is Tarrant County, with an emphasis on approximately 345 square miles (38%) of the county, which is classified as rural/unincorporated or non-urban cities and towns.

Major Activities and Deliverables:

● Deliver public awareness activities to 35,000 caregivers over the term of the project.
● Expansion of the 2-1-1 respite care resource database to include for-profit providers.
● Develop new emergency respite services.
● Create a “Respite Co-Op,” which will be developed by the Arc of Tarrant County and the IDD Council as a mechanism for parents/caregivers of people with IDD to take turns caring for one another’s loved one on a volunteer basis.

Local Partners:

● ADRC of Tarrant County (lead)  
● Area Agency on Aging of Tarrant County  
● ARC of Greater Tarrant County  
● Cuidado Casero Home Health  
● Easter Seals North Texas  
● Fort Worth Hispanic Chamber  
● Fort Worth Mayor’s Committee on Persons with Disabilities  
● Mental Health/Mental Retardation of Tarrant County - MR/IDD Services  
● IDD Needs Council of Tarrant County  
● Outreach Health Services  
● Resource Centers on Independent Living  
● Stonegate Nursing Center  
● 2-1-1 Tarrant County  
● Vietnamese Nationals Community of Greater Fort Worth
• Wilcare In-Home Care

Staffing:
The ADRC will staff this project with 1 quarter-time project coordinator, two quarter-time service navigators, plus contracted services from partners listed above.

How This Contract Will Enhance the Coordination of Respite Services in Texas:
By sharing protocols, systems, lessons learned, and through active engagement with the TRCC and the Coalition, the Tarrant County Lifespan Respite Care Program seeks to expand access, address gaps in services for caregivers, and reduce fragmentation in respite care services available throughout the region. Specifically, this project will utilize the ADRC of Tarrant County as an access point to focus on three segments of the population within the rural areas of Tarrant County currently underserved by existing respite care programs, which include:

• caregivers of adults with physical disabilities, ages 21 – 59, with an emphasis on those who are Hispanic, Vietnamese, and living in rural parts of Tarrant County, who are not eligible for Medicaid, and with incomes less than 300% of poverty level;
• caregivers of adults with IDD, ages 21 – 59 and who are not currently eligible for existing respite services. These may include individuals on the Medicaid Waiver interest lists or other state-funded interest lists who are not eligible for Medicaid, and with incomes less than 300% of poverty level. Many individuals are placed on the interest list prior to having a determination of Medicaid eligibility.
• Older adults with Alzheimer’s disease and their caregivers.

ADRC of Central Texas

Grant Amount:
$238,500

Number Impacted and Cost per Person Anticipated:
150 caregivers with a cost limit of $1,200 per caregiver.

Overall Goal:
Improve access and coordination, increase availability of respite services for caregivers supported by existing leadership of the ADRC partner agencies, and develop a partnership with Temple College to train respite care providers.

Geographical Region:
The service area will be five counties with a special emphasis on reaching isolated caregivers living in the rural areas of Hamilton, Lampasas, Coryell, and Milam counties. Additionally, special efforts will be made to outreach to the American Asian Pacific Islander population residing in the Killeen area.
Major Activities and Deliverables:

- Develop coordination mechanisms for the ADRC partner agencies to identify high-risk caregivers among their targeted service populations.
- Establish procedures for the ADRC partner agencies to provide caregivers access to expanded respite services.
- Establish a partnership with the Temple College Community Education and the Schmieding Center for Senior Health and Education to create a “Center for Caregiver Excellence” with the goal of increasing the knowledge, skills and abilities of both paid and unpaid caregivers.

Lead Agency and Partners:

- ADRC of Central Texas (lead)
- Children with Special Needs Network
- Early Childhood Intervention
- Mental Retardation Authority
- Heart of Central Texas Independent Living Center
- Scott & White – Program on Aging & Care
- DADS’ local Community Services office

Staffing:
The Area Agency on Aging of Central Texas will be the administrative entity and dedicate one-tenth time of oversight from its director, as well as a contract manager at one-fifth time, plus contracted services from the ADRC Project Leadership Team which is comprised of the seven agencies mentioned above.

How this Grant Will Enhance Coordination of Respite in Texas:
Through this grant, this contractor and its partners will assist the TRCC and the Coalition fulfill the mission to create an inventory of statewide respite programs, develop outreach materials to identify caregivers in need of respite, compile best practices, and creating a replicable program toolkit. Additionally, increased respite services will be made available to targeted high-risk caregivers caring for individuals of any age, with any chronic health condition and/or disability among the ADRC partners. Services will be cost effective for the community and can be replicated across Texas.

Area Agency on Aging of the Capital Area

Grant Amount:
$361,000.00.

Number Impacted and Cost Per Person Anticipated:
100 caregivers with an approximate cost of $1,200 - $2,000 per person.
Overall Goal:
To expand available respite services in the region, assist caregivers who are ineligible for other respite programs, and increase awareness of the availability of respite services.

Geographical Region:
The service area comprises ten counties located within the greater Capital area and includes Bastrop, Blanco, Burnet, and Caldwell, Fayette, Hays, Lee, Llano, Travis and Williamson counties. This area covers approximately 8,571 square miles, and is a mix of the urbanized communities along the IH-35 corridor, as well as numerous extremely rural areas.

Major Activities and Deliverables:

- Expand awareness of respite services through outreach/educational events, the keystone of which will be a conference open to all caregivers, “Striking a Balance,” hosted with Austin Groups for the Elderly (AGE) in 2010 and 2011.
- Work with RSVP/Travis County to develop volunteer-based respite services, which will serve as an additional opportunity for older individuals to address critical community needs.

Lead Agency and Partners:

- Area Agency on Aging of the Capital Area (lead)
- Austin Groups for the Elderly
- Bluebonnet Trails Mental Health/Mental Retardation
- Austin Travis County Integral Care
- Casey Family Program
- Helping the Aging, Needy and Disabled, Inc.
- Mike’s Place/Meals on Wheels
- Texas Legal Services
- Older Adult Rural Services.

Staffing:
The AAA will staff this grant through one full-time Respite Project Coordinator, a Program Manager at one-quarter time, and one-tenth time for the Caregiver Support Coordinator.

How this Grant Will Enhance Coordination of Respite in Texas:
Through education, outreach activities, identification of respite providers, volunteers, and expansion of the Caregiver Support program, caregivers will gain greater access to services through the Capital Area Lifespan Respite Program.