Rider 38

Delivery of Caregiver Support Services

August 2010
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Rider 38: Delivery of Caregiver Support Services

As required by the 2010-11 General Appropriations Act (Article II, Department of Aging and Disability Services, Rider 38, S.B. 1, 81st Legislature, Regular Session, 2009), the Department of Aging and Disability Services (DADS) has developed this report on the strategies implemented by DADS after September 1, 2009, to strengthen the delivery of informal caregiver support services in Texas. The report to the Legislative Budget Board (LBB) and the Governor is required to be submitted by September 1, 2010.

Background
Informal caregivers, those 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 U.S., many Texans are unprepared to assume the role of caregiver when the time comes. Assisting Texans in preparing for and sustaining their roles as caregivers has a positive impact not only on the individuals receiving care, but also by avoiding long-term services and supports costs which 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.

Through a coordinated system involving 28 area agencies on aging (AAAs) and nine Aging and Disability Resource Centers (ADRCs), DADS is working to deliver services and supports to enable and encourage informal caregivers to prepare for and sustain their caregiving roles. As the designated State Unit on Aging, DADS is responsible for administering programs and services under the federal Older Americans Act (OAA) for older persons, their family members and other caregivers. To accomplish this, DADS designates, contracts and provides oversight for AAAs. AAAs provide assistance in locating and accessing community services. Based upon the local needs of individuals in their service area, AAAs also provide nutrition, in-home and other support services, as well as services specifically targeted to informal caregivers.

1 Texas Department of Aging and Disability Services, Informal Care in Texas: Aging Family Caregivers and their Need for Services and Support, October 2009.
2 Texas Legislative Budget Board, Texas State Government Effectiveness and Efficiency, January 2009.
4 Texas Legislative Budget Board, Texas State Government Effectiveness and Efficiency, January 2009.
ADRCs serve as a “no wrong door” to improve consumers’ access to long-term services and supports at the local level. Within each entity, caregiver support coordinators and system navigations are available to assist caregivers in effectively planning, arranging and coordinating services to meet the identified needs of the caregiver. The ADRC initiative began in 2005 with a federal grant from the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services. Today, there are nine ADRCs operating around the state, including:

- 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), and
- El Paso and West Texas (El Paso, Hudspeth, Culberson, Jeff Davis, Brewster, and Presidio counties).

The goal is to establish ADRCs in each of the 11 Health and Human Services (HHS) regions, which will allow DADS to meet a recent requirement from AoA for states to expand ADRCs statewide within the next five years. Given the large geographic areas of the HHS regions and the need for ADRCs to be visible and easily accessible locally, DADS envisions establishing a total of 20 ADRCs throughout the state by the year 2020. To begin, DADS plans to establish two ADRCs in early fiscal year 2011 in regions not currently served by an ADRC.

In June 2009, the Governor signed two pieces of legislation directed toward identifying caregivers and improving the delivery of caregiver support services in Texas: Senate Bill (S.B.) 271, 81st Legislature, Regular Session, 2009, relating to informal caregiver support services; and House Bill (H.B.) 802, 81st Legislature, Regular Session, 2009, relating to the creation of the lifespan respite care program. Both became effective on September 1, 2009.

In addition to conducting implementation activities for these bills, DADS actively sought federal grant funding in fiscal year 2010 to further improve caregiver support services available in this state. The following are detailed summaries of the activities undertaken by DADS during fiscal year 2010 to improve the delivery of caregiver support services.

**Informal Caregiver Support Services**

S.B. 271 incorporates the 2009 recommendations of the LBB relating to strengthening informal caregiver support services including raising public awareness about caregiving and available support services; implementing a caregiver status form into the existing Medicaid functional eligibility determination process; standardizing a caregiver assessment and protocol for

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caregivers accessing services through AAAs; and performing analysis of the data collected from the caregiver status form and caregiver assessment form. In addition to the requirements of S.B. 271, the LBB recommended a rider be included in the 2010-11 General Appropriations Act directing DADS to submit this report.

Public Awareness
In October 2009, DADS published a report, 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 focuses on the aging Texas population of family caregivers and describes the role these family caregivers play in ensuring the individuals under their care are able to remain in their homes. The report concludes:

“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 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.”

To promote AAAs as the resource for answers on aging, DADS is developing a coordinated, statewide multimedia marketing campaign kit for use by AAAs. The kit will contain sample brochures, bookmarks, flyers, posters, news articles, sample public service announcements for radio and TV, etc. in an electronic media format. This kit would be easily replicable and uniform across the state. Use of these materials is expected to increase public awareness of the services and supports available through AAAs. In addition, the 2010 federal continuation grant for ADRCs included a new 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 the professionals’ awareness of the existence of ADRCs, as well as the availability of system navigation and options counseling services.

DADS is developing a procedure for issuing a caregiver letter and resource list, which will be mailed by the regional office to every caregiver identified on the Caregiver Status Questionnaire (CSQ), for who mailing information is available. DADS will expand the list of resources available in its Long Term Services and Supports, Services for Adults and Children with Medical/Physical Disabilities, until such time as more comprehensive caregiver resources are developed by the Texas Respite Coordination Center (TRCC). These resources should be available early 2011.
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, ADRCs, and links to a variety of web-based tools and materials. Calendars will be distributed in hard copy to the ADRCs and the TRCC, and will also be disseminated electronically to the member agencies of the Texas Respite Coalition (TRC), who will make the electronic copies available for download on their respective websites.

When consumers and caregivers attempt to access long-term services and supports through traditional means, they often have to contact multiple agencies and confront confusing and time-consuming applications and eligibility processes. Staff working in ADRCs are highly skilled in helping individuals and their caregivers navigate through the system and make informed decisions. Program evaluations and consumer satisfaction surveys have consistently shown ADRCs are a visible and trusted source of information and assistance for individuals of all ages who have physical or intellectual disabilities. Over the past year, one Texas ADRC has received two national awards for its efforts to streamline access and expand the availability of support services for caregivers.

- In October 2009, the Rosalyn Carter Institute for Caregiving (RCI) awarded its Rosalyn Carter Leadership in Caregiving Award to the ADRC of Central Texas and its partner, the Scott & White Healthcare System, for providing a seamless array of support services to caregivers in the Central Texas region, including the evidence-based REACH II intervention which allows caregivers to be more easily identified, assessed and referred to services determined by their current level of risk. RCI recognizes innovative partnerships between community agencies and caregiving researchers that bridge the gap between science and practice.
- In February 2010, AoA held its first annual Excellence in Action Awards program and awarded the “Changing Lives Award” to the ADRC of Central Texas for their efforts to create and leverage diverse partnerships to bring evidence-based programming for family caregiver to the community. The evidence-based programs currently offered to families include Chronic Disease Self-Management, Matter of Balance, Central Texas Support Teams, REACH II, Savvy Caregiver and Care Transitions.

Both AAAs and ADRCs provide ongoing education and training to caregivers to assist them in making decisions and solving problems associated with caregiving. AAAs also routinely disseminate information for informal caregivers, grandparents or relatives caring for children 18 years of age and under; and the public through publications, large group presentations, seminars, health fairs and mass media. ADRCs also disseminate information to caregivers through these same outlets, including caregivers of persons with disabilities.
As required by the federal grants, all ADRCs have developed print materials and created plans for their dissemination to consumers, caregivers and professionals. Examples include:

- The ADRCs of Tarrant County, Bexar County, North Central Texas and East Texas use electronic messaging for news and resource dissemination. Specifically, the projects use the software Constant Contact for monthly email marketing, either on a bi-weekly, weekly or monthly schedule.
- The ADRC of North Central Texas created a “First Aid Kit” for hospital discharge planners, providing them with 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.
- The ADRC of Tarrant County 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 ADRC of Dallas County provides 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.

Many AAAs maintain resource libraries and other informational resources which caregivers may access. Both AAAs and ADRCs utilize their partnerships with local 2-1-1 Area Information Center (AIC) partners to maintain key linkages to existing 2-1-1 resource databases and to enhance referrals wherever possible. Seven of the 28 AAAs also operate the 2-1-1 (AIC) in their region.

All AAAs maintain websites which provide information concerning services available in its service area, educational information, and links to other aging related websites. The DADS website http://www.dads.state.tx.us/services/faqs-fact/aaa.html complements these marketing tools and provides consumers with information on the types of services which may be delivered locally. DADS also maintains a website dedicated to information about ADRCs http://www.dads.state.tx.us/services/adrc/locations.html.

All ADRCs in Texas are required to develop their own websites as a point of access and to increase public awareness of ADRC services and community resources. As of May 2010, six of the nine ADRCs have fully operational websites. The remaining three are in the development phase.
Caregiver Status Questionnaire and Caregiver Assessment Development

A CSQ was developed to identify and collect information pertaining to primary informal caregivers and is 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 automated intake system for the following programs: Community Care for the Aged and Disabled, Community Based Alternatives, and the In-Home and Family Support Program (IHFSP). 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 is attempted. Identification of the caregiver is voluntary by the person who makes contact with intake staff.

A Caregiver Assessment (CA) was developed to assist in identifying needs and appropriate services for caregivers accessing services through AAAs. Results of the CA are used to develop an individual plan of care, as appropriate. A CA will be completed on all caregivers receiving Care Coordination or Caregiver Support Coordination funded through Title III-E of the OAA. The OAA defines caregivers as “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual…” 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.”

The data collected will be entered into the automated data system and will be used to identify caregivers meeting the OAA priority populations and to identify target populations for outreach and public awareness efforts. The caregiver seeking service through the AAA may not disclose the source of their referral; therefore, some duplication of data can be expected for consumers completing the CSQ and referred to an AAA for caregiver supports by the regional intake office. Neither the CSQ nor the CA has the capability of assigning level of risk. However, AAAs may use the CA, along with the Caregiver Intake and other risk assessment tools, to target services to eligible caregivers.

DADS worked from September through December 2009 to plan implementation activities and to develop the CSQ and CA forms. In the fall, input was sought from long-term services and supports regional directors and regional community care intake workers and screeners on a draft of the CSQ and its use during the Medicaid functional eligibility determination process. This feedback was incorporated into the CSQ. Because the CSQ and the CA both contain demographic information vital to developing a profile of caregivers in Texas, any modification to the CSQ required the same modification be made to the CA.

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6 Ten of the 11 regions use NTK to capture IHFSP.
Local AAA directors and staff were made aware of the DADS plan to implement the provisions of S.B. 271 throughout the fall of 2009. DADS staff attending meetings of the Texas Association of Area Agencies on Aging and the Texas Association of Regional Councils shared information with AAA directors and Councils of Governments staff. In January 2010, a teleconference was held with AAA directors statewide to solicit their review and comments on the CA. A draft of the CA form was released to AAA directors across the state for review and comment by their staff. Comments and concerns were considered and incorporated into the CA. Modifications to any demographic question or answer, which is shared with the CSQ, resulted in a change to the companion form as well.

Also in January, 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 limited pilot. Results of the pilot were discussed during a debriefing teleconference with regional representatives.

The CA was 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 the AAA pilot and debriefing were incorporated into the CA and the CSQ.

Over the ensuing months, staff worked to incorporate the approved versions of the CSQ and the CA into the respective automated data systems. These efforts led to the successful deployment of the CSQ on August 2, 2010, and the successful deployment of the CA on August 9, 2010. Efforts to develop reports, which will enable DADS to extract data for future analysis, continue.

One of the automated data systems, the State Unit on Aging Programs Uniform Reporting System, is a system for both DADS and AAAs. Deployment of the new system began in June 2010 and is expected to be complete by November. Local AAAs are required to implement the use of the CA and to enter information into the automated system, once the system has been implemented by their agency.

*Data Analysis*
DADS will conduct an analysis of the data collected and reported through the automated data systems prior to submitting the report by December 1, 2012, as required by S.B. 271.

*Lifespan Respite Care Program*
As a result of extensive input from numerous advocates, stakeholders and state leaders regarding the needs of caregivers, Texas was well positioned to implement a lifespan respite care program, as required by H.B. 802. In fact, DADS has several significant advantages to help ensure such a program will be successful, including a close coordination with the TRC and ADRCs.
In 2009, DADS entered into a memorandum of agreement with the TRC 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 TRCC. Originally formed as the smaller “Texas Respite Resource Network” in the late nineties to provide input to the state about the delegation of nurse tasks in the provision of in-home services, the TRC is comprised of more than thirty members and is supportive of DADS efforts to coordinate the accessibility and availability of respite care for caregivers. The TRC represents 35 agencies and organizations. Approximately 20 percent of their membership is comprised of caregivers, who themselves are caring for individuals of various ages with disabilities and chronic health conditions.

Working with the TRC and other partners, DADS is working to achieve two outcomes: (1) increasing caregivers’ knowledge about and access to, a wider array of respite care options; and, (2) developing a respite care system with greater capacity, which is more coordinated across service systems. The first outcome will not be measured until 2012, at which time a caregiver survey will be conducted to reveal whether or not the Texas Lifespan Respite Care Program’s multi-layered efforts to raise caregiver awareness have worked.

In September 2009, DADS received $200,000 in funding from the AoA to implement a statewide respite program (the Texas Lifespan Respite Care Program) to enhance and expand the coordination and availability of respite services in the state. The objectives for the Texas Lifespan Respite Care Program include: (1) the creation of the TRCC; (2) increasing the availability of respite services; (3) implementing a caregiver awareness campaign; and, (4) developing best practices, materials and tools for respite care providers. Combined with the general revenue appropriated to DADS to implement H.B. 802, total program funding is currently $1.3 million.

DADS achieved the project’s first objective in May 2010, when DADS entered into a contract with the Texas Association of Regional Councils to create the TRCC. DADS is making progress toward the second objective of increasing the availability of respite services. Work toward the project’s last two objectives, implementing a caregiver awareness campaign and developing best practices materials and tools for respite care providers, will begin during the second half of fiscal year 2010, as the TRCC becomes operational and begins implementation of its work plan.

The objectives of the newly created TRCC are to: (1) support the respite coordination and outreach efforts of the TRC, ADRCs and contractors of respite under H.B. 802; (2) compile and annually update a Texas Inventory of Respite Services, (3) conduct respite forums across the state; (4) develop media kits and outreach materials aimed at caregivers; and, (5) develop training and best practice tools for providers of respite services. The resources and outreach materials developed by the TRCC will be used in meeting the public awareness requirements of S.B. 271 as well. TRCC expects to have the first iteration of the Texas Inventory of Respite Services ready in early fiscal year 2011.
In March 2010, DADS released a competitive request for proposals (RFP) to fund at least three community-based organizations to expand the availability of respite services for caregivers caring for individuals of any age with any chronic health condition(s) and/or any disability as directed by H.B. 802. Disability populations include individuals with intellectual, other cognitive and developmental disabilities, and individuals with physical disabilities. The pilot sites have the responsibility for assisting caregivers who are not eligible for respite services through other programs. As of August 2010, three proposed sites have been selected and are pending contract negotiations.

The TRC provided extensive input into the development of both RFPs released by DADS and is already having a significant impact in its ability to disseminate key program information to numerous providers and advocates of respite services.

**Community Living Program**

During the past two years, DADS and its local partners have been working to identify and implement 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 a Community Living Program (CLP) 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. In September 2009, DADS was awarded a new two-year grant from AoA to support an additional CLP between DADS, the AAA of Tarrant County and the ADRC of Tarrant County.

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) inability to leave the care recipient alone; 3) high levels of stress versus satisfaction; 4) physical burden and declining health of caregiver; 5) care recipient’s behavioral problems; and, 6) desire to institutionalize the patient (as measured by the standardized REACH II Desire to Institutionalize9 instrument).

Upon identifying a high-risk consumer, staff working as care transition specialists use a multi-team care transition process developed by the University of Colorado Health Science Center. 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.

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9 Funded by the National Institute on Aging and the National Institute of Nursing Research, REACH II is a measure/intervention designed to maximize outcomes by systematically targeting several problem areas tailored to each individual caregiver. REACH II is believed to be the first of its kind to assess the efficacy for a multi-component caregiver intervention.
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" indicative of a worsening condition, with instructions about how to respond to them.

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 July 2010, DADS applied for a new Health Care Reform Act grant through AoA, which if received will be used to expand the care transition model in the ADRC of Central Texas to additional individuals and their caregivers throughout a broader area of the region and working in partnership with a second hospital system located in Killeen, Texas.

**Summary**

DADS has worked to strengthen caregiver support services over the past year, including the development and implementation of the CSQ and the CA, expansion of the ADRC initiative, and steps toward promoting awareness of caregiver resources. The creation of the TRC and the TRCC is enabling DADS to advance the provision of services in Texas for caregivers of any age including spouses and family members caring for older individuals with chronic healthcare needs; grandparents caring for children; biological, adoptive and foster parents caring for children with special needs; and, any individual caring for adults with intellectual, cognitive, developmental and physical disabilities and/or chronic conditions.

Over the next 12 months, DADS will enter into contracts to establish three Lifespan Respite Care pilot projects with the goal of expanding the availability and awareness of respite services within specific geographical areas. The pilot sites will be a key component of the Lifespan Respite Care Program developed under H.B. 802. The production of the Texas Inventory of Respite Services by the TRCC in early fiscal year 2011 will be an important step toward increasing public awareness of available caregiver resources. Local AAAs, DADS regional community services intake offices, and ADRCs across the state will utilize this publication as well as the media tool kit being developed by DADS as outreach tools to increase the awareness of available caregiver resources. In addition, the establishment of two additional ADRCs by DADS in 2010 will advance the DADS goal of empowering individuals and their caregivers to make informed choices about services and supports, and to streamline access to long-term services in Texas.