



# **A PROFILE OF INFORMAL CAREGIVING IN TEXAS**

Report to the  
Texas Legislature

As Required by  
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Submitted to  
Office of the Governor  
and  
Legislative Budget Board



Texas Department of Aging and Disability Services

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# Executive Summary

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.<sup>1</sup> In Texas there are approximately 655,000 older persons and persons of all ages with disabilities who need help with daily activities and who 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.<sup>2</sup> 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<sup>3</sup> who care for older persons and persons with disabilities often determines whether the individuals needing care can remain at home or 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 helps the state avoid 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.<sup>4</sup>

Between October 2010 and February 2012, the Texas Department of Aging and Disability Services (DADS) interviewed 21,622 informal caregivers providing care to individuals seeking or receiving long-term services and supports in Texas. Hispanics were the predominant group of respondents caring for individuals interested in DADS Medicaid and general revenue services, whereas Whites were the largest group of caregivers who were assessed for caregiver services through Older Americans Act (OAA) programs.

The data collected by DADS provides further evidence that relatives (primarily spouses and children) are the basis for informal caregiving in Texas. Although the vast majority of caregivers identified are women, the ratio of female to male caregivers appears to decrease as age increases. This declining ratio may be attributed in part to a shift in the focus of caregiving from a child/parent-care relationship to a spousal-care situation. About one-half of women reported they are caring for a parent or parent-in-law, compared to one-third of males who report they are providing care for their spouse.

DADS also found relative caregivers are more likely to live with their care recipient. Those living in the same household reported slightly higher stress levels than those who do not live with their care recipient. Data also revealed the percentage of individuals living in the same household is higher for caregivers residing in urban areas than for those residing in rural areas.

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<sup>1</sup> Texas Department of Aging and Disability Services, *Informal Care in Texas: Aging Family Caregivers and their Need for Services and Support*, October 2009.

<sup>2</sup> Texas Legislative Budget Board, *Texas State Government Effectiveness and Efficiency*, January 2009.

<sup>3</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, 2004.

<sup>4</sup> Texas Legislative Budget Board, *Texas State Government Effectiveness and Efficiency*, January 2009.

Only about 10 percent of caregivers reported living 11 or more miles away from the individual for whom they provide care.

Geographic distance between caregiver and care recipient also does not appear to be a factor in employment. Less than one-third of informal caregivers were employed. Those who were employed full-time or part-time were asked a variety of questions about the effects of caregiving on employment. Most reported that caregiving had no negative impacts on their employment, although those with full-time jobs reported higher stress levels than those who were employed part-time or not employed at all. A very small percent report having to quit a job in order to continue providing care. Even fewer, only one percent, fear they could lose their jobs.

Through a statewide coordinated system involving 28 area agencies on aging (AAAs) and 14 Aging and Disability Resource Centers (ADRCs) operating in 10 of 11 health and human services (HHS) regions, DADS is working to deliver services and supports to enable and encourage informal caregivers in long-term caring situations to prepare for and sustain their caregiving roles. This report reflects the progress DADS and the State of Texas have made toward identifying caregivers of individuals interested in accessing Medicaid programs operated by DADS; establishing a standardized assessment to be used by AAAs to evaluate the needs of caregivers of individuals eligible to receive OAA services; developing the tools through which the collection and analysis of data will allow one to formulate a profile or portrait of caregivers in this state; coordinating and expanding public awareness and outreach to raise awareness of the services and supports available to assist informal caregivers statewide to prepare for and sustain their caregiving roles; and through the coordination with other state programs establish a mechanism to collect and create an inventory of respite services available statewide, expand outreach efforts, and develop an online resource to assist caregivers in locating the services and supports available within their respective communities.

# A Profile of Informal Caregiving in Texas

## Introduction

As required by Senate Bill (SB) 271 (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 collect and analyze data related to informal caregiver support services in Texas. This report to the Governor and Legislative Budget Board (LBB) is required to be submitted by December 1, 2012.

In September 2010, DADS filed a report with the Governor and LBB as required by the 2010-11 General Appropriations Act (Article II, Department of Aging and Disability Services, Rider 38, S.B. 1, 81<sup>st</sup> Legislature, Regular Session 2009) entitled Rider 38: Delivery of Caregiver Support Services. This earlier report detailed the strategies implemented by DADS to strengthen the delivery of informal caregiver support services in Texas, as of the date of its publication.

Our latest report, A Profile of Informal Caregiving in Texas, picks up where Rider 38: Delivery of Caregiver Support Services left off and further details DADS efforts to assist informal caregivers in long-term caring situations to prepare for, and sustain, their caregiving roles. The report focuses on the analysis of data collected by DADS related to informal caregivers in Texas from October 5, 2010, through March 1, 2012.

## Background

In June 2009, Governor Rick Perry signed two pieces of legislation directed toward identifying caregivers and improving the delivery of caregiver support services in Texas: SB 271 relating to informal caregiver support services, and House Bill (HB) 802 (81st Legislature, Regular Session, 2009) relating to the creation of the lifespan respite care program. SB 271 incorporates the 2009 recommendations<sup>5</sup> of the Legislative Budget Board (LBB) relating to strengthening the delivery of 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 caregivers accessing services through a AAA; and
- analyzing the data collected from the caregiver status form and caregiver assessment form.

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<sup>5</sup> Texas Legislative Budget Board, *Texas State Government Effectiveness and Efficiency*, January 2009.

Planning activities at DADS began in September 2009 with an initial focus on developing the two required forms, which have become known as the Caregiver Status Questionnaire (CSQ) and the Caregiver Assessment Questionnaire (CAQ). In October 2009, a meeting was held with DADS community services regional directors to discuss and solicit input on a draft of the CSQ and its use during the community services intake process. The CSQ was later released for review by regional community care intake workers and screeners. Comments and concerns resulting from the review process were considered and incorporated, if appropriate, into the final version of the CSQ.

Local AAA directors and staff were also made aware of DADS plan to implement the provisions of SB 271 throughout the fall of 2009. DADS staff shared information with AAA directors and councils of governments during meetings with the Texas Association of Area Agencies on Aging and the Texas Association of Regional Councils. In January 2010, a teleconference was held with AAA directors statewide followed by the release of a draft of the CAQ to AAA directors and their staff across the state for review and comment. The comments and concerns resulting from the review were considered and incorporated into the CAQ.

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

The CAQ was tested in selected local AAA pilot sites across the state between February and March 2010. The AAAs of the Concho Valley, Coastal Bend, Deep East Texas, Permian Basin, North Texas, Harris County, Dallas, Panhandle, and West Central Texas participated in the pilot. 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 CAQ and the CSQ.

Over the ensuing months, staff worked to incorporate the approved versions of the CSQ and the CAQ 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 CAQ on August 9, 2010.

One of the automated data systems, the State Unit on Aging Programs Uniform Reporting System (SPURS), is a system used by AAAs at the local level to account for and track services provided to consumers, and is used by DADS, as the State Unit on Aging, to report data to our federal partners and to monitor compliance with requirements in OAA programs. Deployment of the new system began in June 2010. Local AAAs implemented the use of the Caregiver Assessment as the new automated system began rollout agency-by-agency.

The CSQ is being applied to informal (unpaid) caregivers of new interest list consumers as their names are entered into the automated intake (NTK) system for the following programs: Community Care for the Aged and Disabled (CCAD), Community Based Alternatives (CBA), Medically Dependent Children Program (MDCP) and the In-Home and Family Support (IHFS)

program. The NTK system is used to register persons interested in receiving these Medicaid, Title XX, and state general revenue funded services provided through DADS programs.

The CSQ attempts to identify and collect information pertaining to the primary informal caregiver of the individual whose name was placed on a program interest list. Completion of the CAQ occurs for all caregivers receiving Care Coordination or Caregiver Support Coordination funded through Title III-E of the OAA. Because the CSQ and the CAQ share demographic questions vital to developing a profile of caregivers, any modification to either form requires the same modification be made to the other form.

DADS recognizes some duplication of data is expected for consumers who completed the CSQ and were referred to a AAA for caregiver supports. The caregivers referred by the regional intake are not asked and may not disclose the source of their referral when accessing services through the AAA.

## **Discussion**

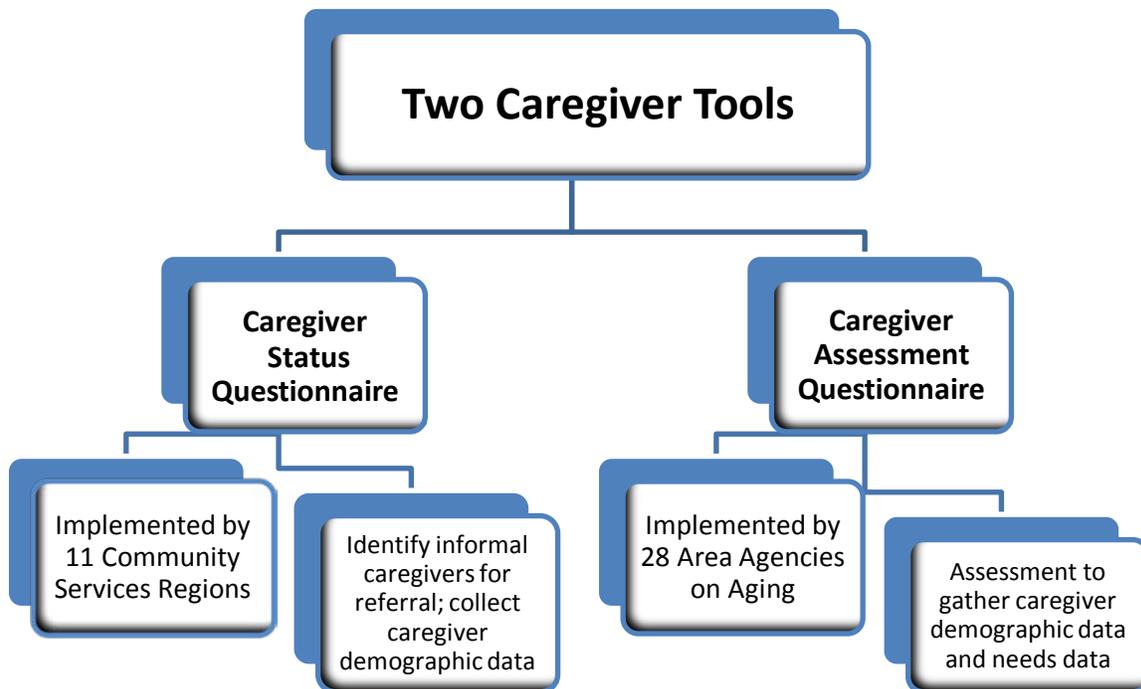
When services are requested to enable an individual to maintain their independence in the community, the caregiver often plays a crucial role. The caregiver can be a main point of contact for physicians, home health providers and others to gain information about the individual, to assist in developing a service plan to meet the individual's needs, and to help coordinate health care and supportive services. The caregiver is an invaluable asset, and often times, the availability of a caregiver is the link that enables the individual needing care to continue living in their own home and remain part of their community. Sustaining and supporting informal caregivers should continue to be a primary topic for future policy and practice directions.

It is the expectation of SB 271 that the data collected and analyzed, as a result of this initiative, will be used by DADS to evaluate the needs of assessed informal caregivers; measure the effectiveness of certain informal caregiver support interventions; improve existing caregiver support programs; develop new services for caregivers; and determine the effect of informal caregiving on employment and employers.

## Development of Tools to Profile and Assess Informal Caregivers

The CSQ is used during the intake process for DADS community services and Medicaid programs, including CCAD, CBA, MDCP and IHFS. The CSQ occurs at the time of the intake telephone contact and attempts to identify and collect information pertaining to the primary informal caregiver of the individual whose name was placed on a program interest list. DADS does not require intake staff to complete a CSQ for anyone other than the primary informal caregiver. The questions in the CSQ allow DADS to gain a demographic profile of the caregiver without assessing the needs of the caregiver. However, the CSQ is also used to refer persons who may qualify for services provided through AAAs.

Completion of the CAQ occurs for all caregivers receiving Care Coordination or Caregiver Support Coordination funded through Title III-E of the OAA. The CAQ is designed to assist in identifying needs and appropriate services for the caregiver and may be completed in person or by phone. AAAs use the CAQ to develop an individual plan of care based upon results from each individual assessment, as determined to be appropriate.



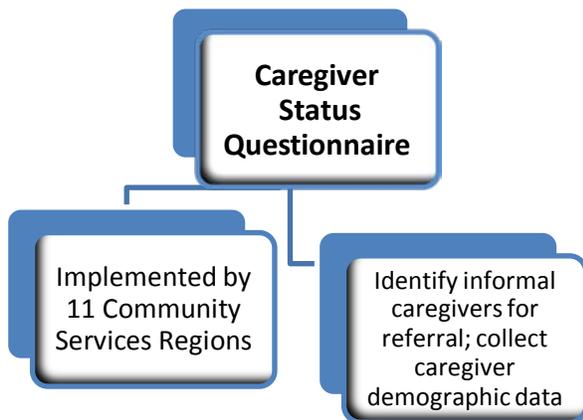
While some AAAs had previously developed and were using assessments for services under the National Family Caregiver Support Program of the OAA, no single assessment of needs for caregivers had been developed for consistent use across the state. Neither the CSQ nor the CAQ

has the capability of assigning level of risk; however, AAAs may use the CAQ, along with the Caregiver Intake and other risk assessment tools<sup>6</sup>, to target services to eligible caregivers.

DADS staff extensively studied and reviewed assessment tools from a wide variety of sources prior to drafting a recommended document. Resources included existing Texas AAA assessments, national caregiver information clearinghouses, other states' documents, evidence-based caregiver interventions, university caregiver research studies and other data. The review focused on common data elements across assessments, questions relevant to the legislative requirements, common caregiver identification questions, issues related to employed caregivers and stress/burden measurement tools.

Stakeholder groups were engaged for response to the final draft of the CAQ and the CSQ. Each question for each tool was reviewed for clarity, content, language and format. The protocol for administering each tool and the quality of each question to produce good analytical data was also evaluated. In August 2010, the project was launched.

In response to the SB 271 requirement to implement a caregiver status form into the existing Medicaid process, the CSQ was developed to identify and collect information pertaining to primary informal caregivers. The CSQ was developed as a survey for the caregivers of individuals requesting long-term services and supports through the DADS intake system. The questions are designed to provide DADS with a demographic profile of the caregiver and are not intended to assess the full range of needs of the caregiver. The purpose of the questionnaire is to identify informal caregivers for referrals to appropriate support services and to develop a profile of caregivers.



The CSQ is used to gather information about informal, unpaid caregivers of individuals seeking DADS services who are entered into the automated intake system for community-based long-term services and supports, including CCAD, CBA, MDCP and IHFSP<sup>7</sup>. The intake system is used to register persons interested in receiving Medicaid services provided through DADS programs.

In addition to developing a profile of caregivers in Texas, the CSQ provides an opportunity to identify issues that might impact the caregiver's ability to assist the individual. Appropriate

referrals by intake staff are based on the caregiver's needs. By design, intake staff refers caregivers to the AAA if it is determined the caregiver meets eligibility screening criteria.

<sup>6</sup> Caregiver risk assessment tools measure the risk for institutionalization for the care receiver that can result from challenges of caregiving.

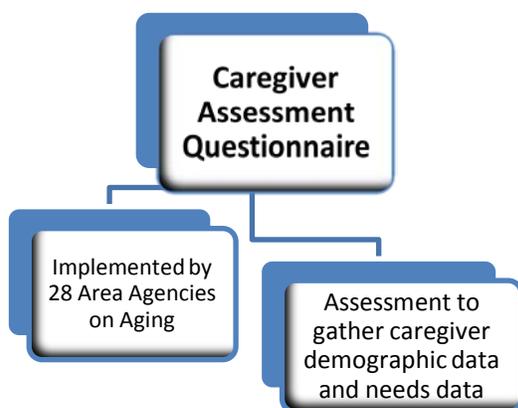
<sup>7</sup> Ten of the 11 regions used NTK to capture IHFSP data during the period for which data is analyzed.

Individuals are also referred to other local resources. Eligibility screening criteria for AAA services included in the CSQ are:

- 60 years of age or older and is caring for an individual of any age;
- 55 years of age or older and:
  - is caring for a grandchild under the age of 18 in his/her home because the biological or adoptive parents are unable or unwilling; or
  - has legal custody or guardianship or is raising the child informally; or is caring for a recipient age 19-59 with severe disabilities; or
- a caregiver for an individual of any age with Alzheimer’s disease or dementia.

An individual may request DADS services by telephone, mail, fax or in person. Other agencies, organizations, friends and family may also contact DADS to request information on behalf of the individual. Individuals in need of services can be of any age, and caregivers comprise a wide range of age groups. When a request for DADS services is received, DADS staff provides general information about DADS, determines the type of service being requested, refers the individual to the appropriate DADS program, and makes referrals to other state or community agencies if applicable. At this point, the information gathered by DADS staff is entered in the NTK system to begin the assessment process for services or to be placed on an interest list.

The CSQ is completed by DADS staff at the time of intake contact. If a caregiver to the individual requesting services is identified, and the caregiver is available to speak with DADS staff, DADS staff asks the questions on the CSQ and enters this information in the NTK system. When 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.



In response to the SB 271 requirement to standardize a caregiver assessment and protocol for caregivers accessing services through AAAs, the CAQ was developed to assist in identifying needs and appropriate services for caregivers accessing services through AAAs statewide. The CAQ incorporates the identical questions used in the CSQ to develop a profile of Texas caregivers.

Results of the CAQ are used to develop an individual plan of care, as appropriate. A CAQ is completed for all caregivers receiving Care Coordination or Caregiver Support Coordination funded through Title III-E of the OAA.

The OAA defines a caregiver as “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual...”<sup>8</sup> A grandparent or

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<sup>8</sup> Older Americans Act, as amended in 2006, 42 U.S.C. §3022.

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.”<sup>9</sup>

The data collected are entered into the statewide-automated data system and 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 indicate the source of referral; therefore, some duplication of data can be expected for consumers completing the CSQ and referred to a AAA for caregiver supports by the regional intake office.

Effective in 2010, and as a result of SB 271, caregiver needs are consistently assessed by each of the 28 AAAs in Texas using the CAQ. The CAQ was developed as an assessment tool for caregivers seeking help through AAAs who meet the eligibility criteria as defined by the OAA. The purpose of the assessment is to assist in identifying needs and appropriate services for caregivers accessing services through AAAs and, when appropriate, to develop an individual plan of care. It also assists the AAA to identify caregivers meeting the OAA priority populations and to identify target populations for outreach and public awareness efforts. Resulting data may also be individually analyzed by the AAA for service planning purposes.

While the CAQ identifies the major roles of the caregiver, it also identifies areas in which a caregiver may need education or training to enhance the knowledge and skills needed for an individual’s circumstances. It guides the professional conducting the assessment to help the caregiver identify how a more family-centered approach to caregiving can be achieved, and addresses the physical and mental health status of the caregiver.

Following the initial implementation phase, five AAAs were randomly selected and asked if the assessment had resulted in any positive, unexpected outcomes. Some AAAs reported the process has greatly assisted in care planning, but more importantly, it has helped caregivers identify their own needs – even the fact they are, indeed, a caregiver. According to one AAA, caregivers feel empowered to do more, or something different, with their loved one and they experience for the first time interest in them as a consumer themselves.

An individual, or another person or agency contacting the AAA on behalf of an individual, may request caregiver support services by telephone, mail, email, fax, or in person. When a request is received, the AAA determines the type of assistance required, which may range from brief information to in-depth caregiver service supports. Services specifically for caregivers include education, information, care coordination, support groups, respite and supplemental services.

The CAQ is completed by AAA staff when a caregiver is provided care coordination, the protocol established by DADS when this mandate was initiated. Information gathered is entered into SPURS using a specialized data entry format.

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<sup>9</sup> Older Americans Act, as amended in 2006, 42 U.S.C. §3030.

## Data Analysis

The data analysis section profiles the characteristics of caregivers responding to the CSQ and CAQ. Respondents to the CSQ were informal caregivers of new interest list consumers for CCAD, CBA, MDCP and IHFSP. Respondents to the CAQ were caregivers receiving care coordination or caregiver support coordination funded through Title III-E of the OAA. The following sections profile caregivers and their experiences with caregiving.

### Caregiver Respondents by County and HHS Region



Of the 17,753 caregivers who responded to the CSQ, 237 of the 254 Texas counties were represented. The following counties experienced the highest number of caregiver calls:

- 1,590 callers – Harris County;
- 1,538 callers – Dallas County;
- 1,139 callers – El Paso County; and
- 1,043 callers – Bexar County.

The U.S. Office of Management and Budget<sup>10</sup> groups counties into the different metropolitan areas across the nation. Those counties designated as part of a metropolitan area are considered urban while those counties not part of a metropolitan area are considered rural. Of

those who responded to the CSQ, more caregivers were residing in urban counties than in rural counties across the state.

Of those caregivers who spoke with DADS, 11,548 lived in 77 urban counties while 2,735 lived in 160 rural counties.

In regards to Health and Human Services (HHS) regions, 54 percent of caregivers identified their city or county to be in regions 3, 6 and 11. Regions with over 1,000 callers each (1, 3, 6, 7, 8, 10, and 11) accounted for 88 percent of callers, while regions 2, 4, 5 and 9 accounted for 12 percent of callers.

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<sup>10</sup> Office of Management and Budget definition: The White House's Office of Management and Budget (OMB) designates counties as Metropolitan, Micropolitan, or Neither. A Metro area contains a core urban area of 50,000 or more population, and a Micro area contains an urban core of at least 10,000 (but less than 50,000) population. All counties that are not part of a Metropolitan Statistical Area (MSA) are considered rural. Micropolitan counties are considered non-Metropolitan or rural along with all counties that are not classified as either Metro or Micro. The OMB definition is easy to use since it designates all the land and population inside a county as either Metro or Non-Metro. For more information on Metro areas, see: <http://www.census.gov/population/metro/>.

The 3,869 caregivers who completed the CAQ represented 212 Texas counties and 646 towns/cities across the state. The top six counties to have caregivers complete the assessment were Tarrant, Bexar, Harris, Dallas, Grayson and Travis. These counties represented the highest number of caregiver assessments completed by county during the initial implementation phase. The number of caregivers assessed by county included:

- 218 residing in Tarrant County;
- 215 residing in Bexar County;
- 218 residing in Harris County;
- 200 residing in Dallas County;
- 166 residing in Grayson County; and
- 110 residing in Travis County.

The CAQ is required only when the caregiver receives support coordination. Eight AAAs (Bexar, Capital, Dallas, East Texas, Harris, Lower Rio, North Central and Tarrant), or 28 percent, assessed more than 50 percent of the total caregivers requesting OAA services. Caregivers are assessed as identified by the AAA rather than being identified when contacting the state for a broad range of services. The number of assessments for each area was not representative of the ratio of the older (age 60 and older) population living in metropolitan or rural areas of the state.

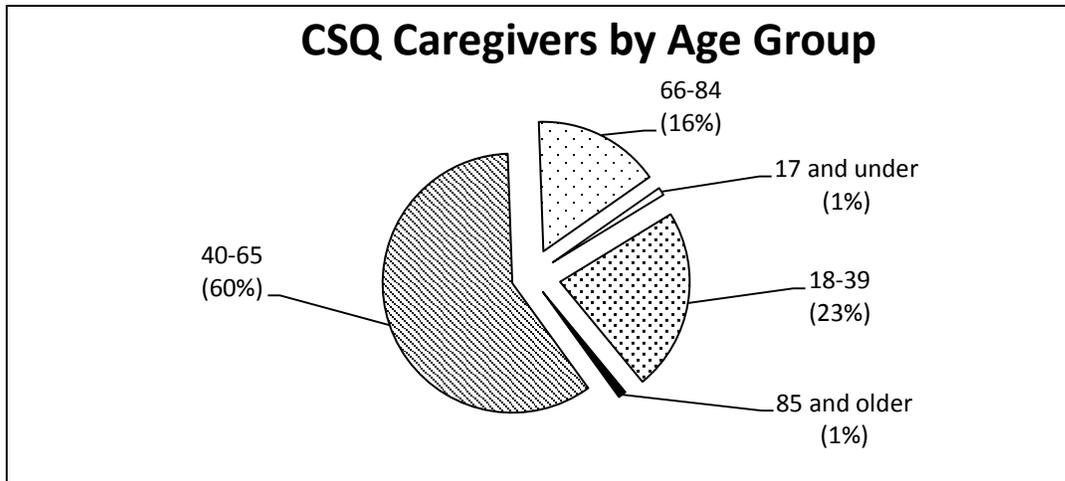
The majority of caregivers assessed (65 percent) were not aware of caregiver support services prior to contacting the AAA for assistance.

### **Demographic Characteristics of Caregivers**

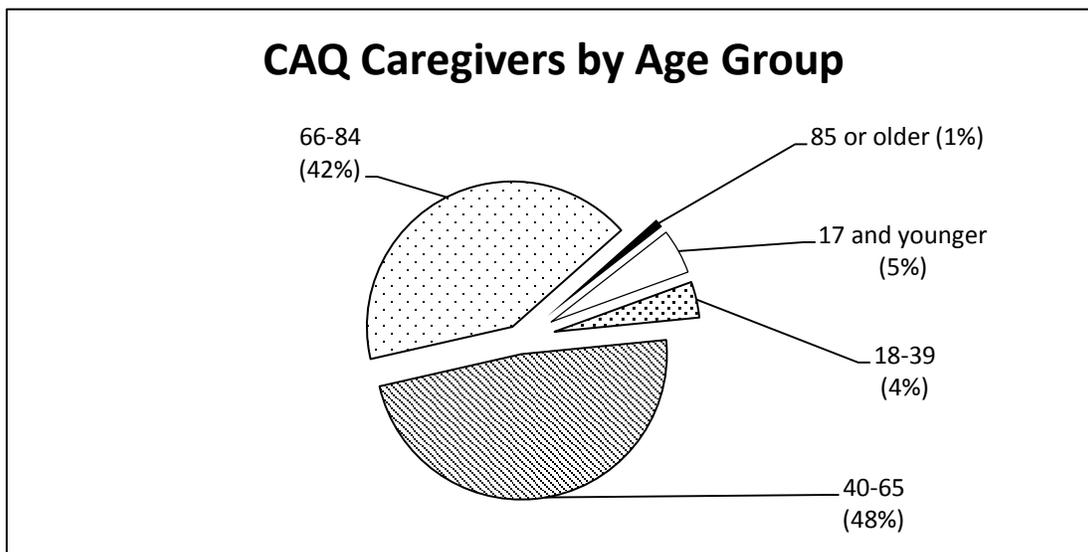
Hispanics were the predominant group of caregivers (38 percent) among CSQ respondents. The next largest group consisted of Whites (36 percent) followed by Blacks/African Americans (25 percent). American Indian/Alaskan Native, Native Hawaiian/Other Pacific Islander, and Asians each made up less than one percent of respondents.

The majority of caregivers assessed by AAAs were White (56 percent), with the next largest group reporting to be of Hispanic origin (23 percent), followed by Black/African American (19 percent). Asians represented 2 percent of caregivers assessed, with American Indian/Alaskan Native and Native Hawaiian/Other Pacific Islander each comprising less than 1 percent.

As the following chart shows, the majority of caregivers were between the ages of 40 and 65, making up 60 percent of CSQ respondents. Caregivers between the ages of 18 and 39 made up the next largest group at 23 percent, followed by caregivers between 66 and 84 years of age (16 percent). One percent of caregivers were 85 or older and less than 1 percent was under age 18.



As was the case with the CSQ, the majority of caregivers assessed through the CAQ were between the ages of 40 and 65, making up 48 percent. Caregivers between the ages of 66 and 84 made up the next largest group at 42 percent, followed by caregivers under age 18 (5 percent) and those between 18 and 39 years of age (4 percent). The remaining 1 percent were age 85 or older.



The CAQ also includes questions about level of poverty. The younger the caregiver, the more likely the caregiver was to be in poverty. Over one-half (51 percent) of caregivers age 18-39 reported being in poverty. For caregivers who are age 40-64, there is a significant drop in the rate of poverty at 36 percent, and for those who are 65 – 84 years, 27 percent reported being in poverty. Nineteen percent of the caregivers age 85 and older reported living in poverty. Women were slightly more likely to report living in poverty than men, 34 percent versus 29 percent.

Seventy-two percent of caregivers overall were female, with females being the majority in all age groups. This figure is lower than the 81 percent of female caregivers responding to the CSQ.

The ratio of female to male caregivers decreased as the age group increased. For caregivers who were 18-39 years of age, 83 percent were female; for the 40-65 age group, 77 percent were female; for the 66-84 age group, 66 percent were female; and for those 85 years and older, 61 percent were female.

### **Caregivers and Relationship to Care Recipient**

Relatives primarily served as the primary informal caregiver. The majority of caregivers were children or spouses of the care recipients. The data reflects 29 percent of men were more likely to be the spouse of their care recipient, while 51 percent of women were more likely to be caring for a parent or parent-in-law. However, differences existed between questions for percentages of children and spouses providing care. Spouses represented 33 percent of caregivers responding to the CAQ and 49 percent of CSQ respondents. Children of the care recipient represented 38 percent of the CAQ data and 18 percent of the CSQ data.

On the CAQ, other relatives, including son/daughter-in-law, grandchild, grandparent, other relative, and sibling, accounted for 14 percent of all caregivers. Friends, neighbors and other non-relatives accounted for fewer than 4 percent of caregivers. On the CSQ, 12 percent were other relatives to the care recipient while grandchildren, grandparents, life partners, or siblings made up 11 percent of caregivers who responded.

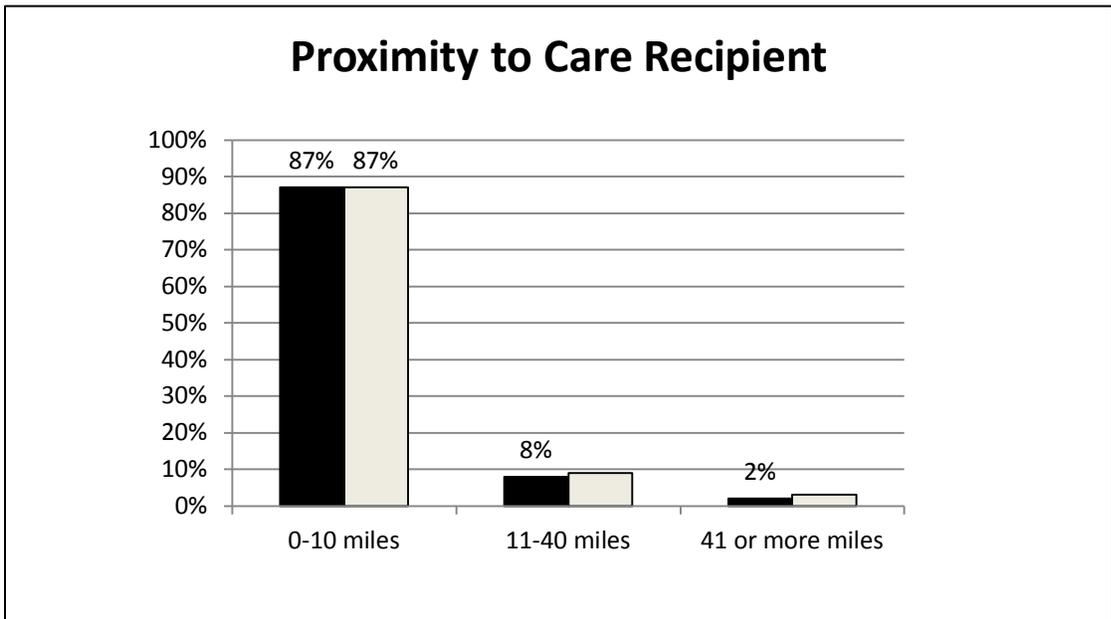
### **Caregivers' Family Composition**

Most respondents to the CAQ reported being married (68 percent) and 84 percent indicated they did not have children under the age of 18. This is similar to the composition of caregivers responding to the CSQ with 69 percent married and 72 percent reporting no children under the age of 18. Non-family members, such as friends, neighbors, and other non-relatives, made up fewer than four percent of caregivers according to the CAQ. More non-family members (9 percent) served as caregivers as reported in the CSQ.

The percent by race/ethnicity who reported having children under the age of 18 was relatively similar among this reporting group. Of the CAQ respondents, 35 percent of Asians, 24 percent of Whites, 20 percent of Black/African Americans, and 24 percent Hispanics reporting this information had children under the age of 18. The CSQ data indicated Asians (34 percent) and Hispanics (32 percent) were more likely to report having children under the age of 18. Among other racial/ethnic groups 23 percent of Whites, 29 percent of Blacks/African Americans, and 30 percent of other racial/ethnic groups reported having children under the age of 18.

### **Proximity of the Caregiver to the Care Recipient**

Most caregivers regardless of race/ethnicity lived with their care recipient with 69 percent (CSQ) and 74 percent (CAQ) respectively. On the CSQ, a higher proportion of urban caregivers, 70 percent, as compared to rural caregivers (65 percent), reported living with the care recipient. The majority (87 percent) of caregivers regardless of age or race/ethnicity lived within 10 miles of the care recipient, as reported on the CSQ and CAQ.



### **Paid vs. Non Paid Caregivers**

The majority of caregivers (97 percent) regardless of race/ethnicity were not paid to provide care to the recipient according to CSQ data. In addition, many caregivers, 73 percent, indicated they were the only non-paid caregiver for the care recipient.

CAQ data reports 98 percent of the caregivers as being nonpaid caregivers<sup>11</sup>. Of the total caregivers assessed, 58 percent reported being the only non-paid person providing care to the care recipient compared to 73 percent of CSQ respondents.

### **Caregiver Time Dedicated to Assist Care Recipient**

Time dedicated to caregiving was examined by frequency and length of time. On the CAQ, the overwhelming majority (98 percent) provided care at least once per week regardless of race or ethnicity. Two percent assisted the care recipient monthly. On the CSQ, 92 percent of caregivers reported providing care every day. About seven percent provided care weekly and about one percent provided care less often than weekly.

Most caregivers had someone to call on in an emergency, as reported on the CAQ (78 percent) and CSQ (65 percent). As a result, almost one-fourth, or 22 percent, of CAQ respondents reported having no other person to call to fill in as caregiver as needed, such as in an emergency. Thirty-five percent of CSQ respondents also did not have someone to call on to fill in.

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<sup>11</sup> The Older Americans Act does not allow funding for services to paid caregivers.

In addition, the CSQ focused on length of time a caregiver had provided care. Thirty-three percent of caregivers had been providing care between one-month and one-year at the time of their interview. Caregivers who had been providing care between 1 and 2 years made up 24 percent. Some caregivers had been providing care between 3 and 5 years (18 percent) and some had been providing care between 6 and 10 years (11 percent). Another 10 percent had been providing care for more than 11 years. Four percent had only been providing care for less than one month.

## **Effects of Caregiving on Employment**

Similarly, over one-half of the caregivers indicated they were not employed on both the CSQ (65 percent) and CAQ (64 percent). Approximately 23 percent of CSQ respondents and 27 percent of CAQ respondents were employed full-time. Those employed part-time accounted for 12 percent of CSQ respondents and 9 percent of CAQ respondents.

<b>Of employed caregivers:</b>
<ul style="list-style-type: none"> <li>• 5 percent reported they had quit their job</li> <li>• 3 percent reported that they had changed work schedules</li> <li>• Less than 1 percent reported taking a second job</li> <li>• 6 percent reported they take leave frequently</li> <li>• Less than 1 percent reported they had exceeded the Family Medical Leave Act (FMLA)</li> <li>• About 1 percent reported they feared losing their job</li> </ul>

According to the CSQ findings, those caregivers who were employed full-time or part-time were asked a variety of questions about the effects of caregiving on employment. Caregivers reported few negative impacts on their employment as a result of providing care to another person.

The Families and Work Institute reports, “Forty-two percent of U.S. workers have provided care for an aging relative or friend in the past five years. About half (49 percent) of the workforce expects to be providing eldercare in the coming years.”<sup>12</sup>

Among CAQ respondents, 31 percent of caregivers with employment reported caregiving responsibilities have affected their work. Effects included decreasing work hours or going part-time, losing wages or having extended leave without pay, and difficulty focusing or concentrating at work.

With regard to race and ethnicity from the CSQ findings, 10 percent of Whites, 5 percent of Hispanics and 4 percent of Blacks/African Americans were more likely than Asians (2 percent) and people in other racial/ethnic groups (2 percent) to have lost wages or to have had periods with no income due to caregiving responsibilities. Hispanics (10 percent), Whites (8 percent), and Blacks (7 percent) were more likely to take leave frequently because of caregiving responsibilities than Asians (3 percent) or people in other racial/ethnic groups (5 percent) were.

<sup>12</sup> K. Aumann, E. Galinsky, K. Sakai, M. Brown, and J. T. Bond, *The Eldercare Study: Everyday Realities and Wishes for Change* (New York, NY: Families and Work Institute, October 2010)

By race or ethnicity from the CAQ findings, Asians were more likely to report being employed full-time at 38 percent. Twenty-four percent of Whites, 29 percent of Hispanics, and 33 percent of Black/African Americans worked full-time. One-half (50 percent) of caregivers reported they currently do not work. Sixty-seven percent of Whites, 57 percent of Blacks/African Americans, and 60 percent of Hispanics assessed do not work either full-time or part-time.

Any discussion of caregivers and employment must begin with the understanding employed caregivers who work in less flexible work environments may not have an option to provide care so they would not be captured in the CSQ or CAQ data. In addition, some caregivers may have had to reluctantly leave a job to care for a loved one, so although they are identified as not employed their caregiving has affected their employment. National statistics indicate, “Once caregiving has started, more than six out of 10 caregivers (62 percent) say they make some sort of workplace accommodation, such as going in late or leaving early, taking a leave of absence, or dropping back to part-time.”<sup>13</sup> DADS CSQ and CAQ data on employment may in part reflect these caregivers who chose to leave the workforce to provide care.

In addition to the personal costs for the caregiver, there is a cost to employers with absenteeism, workplace disruptions and reduced work status. Nationally, businesses lose between \$17.1 and \$33.6 billion per year in decreased productivity of their workforce due to caregiving pressures.<sup>14</sup>

### **Impact of Caregivers’ Health Issues on Caregiving**

Care for others impacts the health of caregivers regardless of race or ethnicity. Fewer caregivers (26 percent) reported on the CSQ having had a chronic health condition or had experienced a recent health crisis as compared to 46 percent of caregivers responding to the CAQ. Nearly 75 percent of CSQ respondents reporting a health condition or recent health crisis indicated their health condition affected their ability to provide care. Of the CAQ respondents, 35 percent stated their health has affected their ability to care for the care recipient, with 11 percent reporting being recently hospitalized.

In fact, the Caregiver Health Effects Study cites, “Elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63 percent higher mortality rate than non-caregivers of the same age.”<sup>15</sup>

### **Stress Level of Caregivers**

The majority of caregivers responding to both the CSQ and CAQ reported caregiving as stressful. Fifty-six percent of caregivers reporting on the CSQ found caregiving to be stressful. Of those who found caregiving to be stressful, 44 percent rated their stress level as moderate.

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<sup>13</sup> National Alliance for Caregiving and MetLife Mature Market Institute. (2010) *Working Caregivers and Employer Health Care Costs*. <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf>

<sup>14</sup> *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business* (2006)

<sup>15</sup> Schulz, R. & Beach, S. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study, *JAMA*, 282: 2215-2219.

Over one-third said their stress level was high, and one out of five respondents indicated their stress level was low.

CAQ data tells us 75 percent of caregivers find caregiving to be stressful, with 30 percent reporting their stress level as high. Similar to the CSQ, 40 percent of caregivers reported moderate stress levels, and 27 percent reported low stress levels.

According to CAQ findings, caregivers were responsive to questions about the impact of caregiving on their stress levels. Eighty-eight percent of caregivers reported they agreed or strongly agreed with feeling a sense of satisfaction helping the care recipient and 83 percent reported feeling confident about providing care. Sixty-one percent of caregivers agreed or strongly agreed providing care while meeting other family and work responsibilities was stressful and 78 percent of caregivers felt they had an obligation to provide care to the care recipient. In addition, 23 percent of caregivers reported they could do a better job of providing care than someone else could.

Forty-two percent reported agreeing or strongly agreeing their finances are strained due to providing care. Overall, Hispanics most frequently reported their finances were strained because of caregiving. Hispanics also reported their own health had suffered, although they could do a better job of caregiving. Financial strain was reported by 44 percent of Asians, 42 percent of Blacks/African Americans, 41 percent of Whites, and 46 percent for Hispanics.

According to the CAQ findings, regardless of race, the majority of caregivers feel some sense of satisfaction in providing care for another person. While 59 percent reported engaging in activities which effectively relieve stress, 30 percent reported activities “somewhat” relieve stress and 11 percent reported finding no effective ways to relieve stress. Sixteen percent indicated they would like information, education, and/or training about how to care for themselves while caring for others.

### Stress and Proximity to Care Recipient

Caregivers who reported living with the care recipient reported slightly higher stress levels than those who reported not living with the care recipient, as reported on both the CSQ and CAQ. Among CSQ caregiver respondents who live with the care recipient, 38 percent reported high stress levels, 44 percent reported moderate, and 18 percent reported low levels of stress. Among those who did not live with the care recipient, 35 percent reported high levels of stress, while 42 percent reported moderate and 23 percent reported low levels of stress. Similar to the CSQ finding, 32 percent of caregivers who reported living with the care recipient rated their stress level as high versus 25 percent of those who did not live with the care recipient.

Stress levels increase the further away a caregiver lives from the care receiver, as CAQ data revealed. High stress levels were reported by 30 percent of caregivers living within 10 miles of the recipient, 25 percent of those living 11 to 40 miles, and 33 percent living 41 to 100 miles away.

## Stress Level of Employed Caregivers

Caregivers reported various stressors in concert with working full-time. On the CSQ, caregivers with full-time jobs were more likely to report higher stress levels than those who were employed part-time or not employed at all. Of those caregivers employed full-time, 40 percent reported high stress levels, and 46 percent reported moderate stress levels. Of those employed part-time, 35 percent reported high stress levels, and 41 percent reported moderate stress levels. Of those caregivers who were not employed, 36 percent reported high stress levels and 44 percent reported moderate stress levels.

Twenty-six percent of caregivers reported working full-time on the CAQ. Of those, 31 percent reported feeling they could do a better job of caring for the care recipient than someone else could. Of the 8 percent of caregivers working part-time, 37 percent reported feeling they could do a better job of caring for the care recipient. Variances in stress levels for employed versus non-employed caregivers were not significant. The majority of caregivers assessed using the CAQ was not employed.

## Impact on Stress Level when Providing Care to More than One Person

Similarly, the majority of caregivers reported on the CSQ and CQA were not providing care to more than one recipient. On the CSQ, 76 percent of caregivers indicated they were not providing care to anyone other than the care recipient. Of those caregivers providing care to more than one person, 40 percent reported higher stress levels as compared to 36 percent of those who provide care to only one care recipient.

Of all caregivers surveyed through the CAQ, 78 percent reported they were not caring for more than one person, similar to those responding to the CSQ. Of those who are providing care for more than one person, 32 percent reported high stress. Twenty-eight percent reported high stress when caring for only one person. Data did not reveal significant variances in stress when providing care to either one or more than one person.

## CAQ Support Tasks Performed by Caregivers

A high percentage of caregivers provide significant assistance when taking care of another person. Seventy-two percent of caregivers reported helping the care recipient with personal care tasks (ADLs) and 85 percent reported helping the care recipient with homemaker chores (IADLs). Eighty-five percent reported helping the care recipient with transportation; 73 percent reported helping the care recipient with managing finances; and 90 percent reported helping the care recipient with health care (doctor visits, medication monitoring). Eighty percent reported the need to provide supervision to the care recipient and 85 percent reported helping the care recipient by providing emotional support.

### **Support Tasks Provided**

Percent of Caregivers Providing Support Tasks	Support Task
72	Personal care tasks (e.g., bathing, grooming, etc.)
85	Homemaker chores
85	Transportation
73	Managing finances
90	Health care (e.g., doctor visits, medications monitoring)
80	Supervision
85	Emotional support

Caregivers assessed reported a high level of responsibility in taking care of the recipient. Eighty-seven percent reported the care recipient requires assistance with three or more ADLs. Five percent reported being a grandparent or older relative age 55 and older providing care for children with severe disabilities. Forty-three percent reported the care recipient has Alzheimer’s disease or related dementia.

With 39 percent of care recipients having been hospitalized recently, and 11 percent of caregivers reporting a recent hospitalization for themselves, it is not surprising 42 percent of caregivers reported that the care recipient is at risk of institutionalization.

### **CAQ Caregiver Knowledge and Acceptance of Support Services**

Most (65 percent) of caregivers were not aware of support services prior to contacting the AAA and 72 percent had not received caregiver support services in the past. Eleven percent of caregivers reported being reluctant to accept outside help. This reluctance to accept outside help was based on a lack of trust of service providers in the home (4 percent), or the feeling no one else can provide care as well as they do (9 percent). Almost a one-third or 27 percent had other concerns about receiving caregiver support, regardless of the fact 92 percent reported their caregiving is likely to continue indefinitely.

### **CAQ Caregiver Knowledge of Care Recipient’s Condition**

More than one-half of caregivers, 60 percent of those responding to this question indicated they felt “very” knowledgeable about the care recipient’s disease or condition. Thirty-six percent reported feeling “somewhat” and 4 percent reported feeling “not at all” knowledgeable about the care recipient’s disease or condition.

Percentages below indicate caregivers who reported they would like information, education and/or training for the following:

### Information, Education, and/or Training

Percentage of Caregivers Wanting More Information	Topics
24	In-home support services
13	How to provide care to an aging individual
13	Support groups
12	Home safety and/or home modifications or equipment
11	Care recipient's disease or condition
11	Long-term care options (insurance and/or other benefits)
9	How to get other family members to help
8	Legal and financial issues, powers of attorney, living will
7	Individual counseling options
5	Short-term respite care in a facility
5	How to choose a long-term care facility
5	Hands-on skills training for personal care tasks (bathing, grooming, etc.)
4	On-line information and supports

Over one-third (36 percent) of those with no knowledge of the care recipient's condition reported a high stress level. Those caregivers with some knowledge were less likely (33 percent) to report a high stress level; and those with a lot of knowledge of the care recipient's condition (29 percent) were the least likely to report high stress. These percentages indicate knowledge of the care recipient's condition may play a part in reducing caregiver stress.

Fifty-nine percent of caregivers reported engaging in activities which effectively relieve stress. However, 30 percent reported their activities were "somewhat" effective at relieving stress and 11 percent reported finding no effective ways to relieve their stress.

## Conclusions

- Most caregivers assessed were between the ages of 40 to 64 years.
- The majority of caregivers were female, but the relation of female to male caregivers decreases as age increases.
- Married relatives have primary responsibility for caregiving to care recipients with whom they reside.
- Caregiving required a long-term commitment with frequent dedication of time to caregiving.
- Most caregivers found caregiving stressful, with a significant number reporting high stress.
- Caregiver knowledge about a care recipient's condition appeared to reduce stress.

- Caregiving responsibilities negatively affected the work of employed caregivers.
- A small percentage of caregivers found no effective way to relieve stress.
- Most caregivers felt caregiving will continue indefinitely, with almost one-half believing the care recipient is at risk of institutionalization.
- Most caregivers were willing to accept help from others.
- Caregivers assessed using the CAQ are very likely to assist a care recipient in a multitude of essential life activities.
- Caregivers assessed using the CAQ most frequently requested information about in-home support services, how to care for an aging individual, support groups, and home safety and home modification.
- Almost one-half of caregivers assessed by AAAs were caring for an individual with Alzheimer's disease.

DADS will continue to analyze data collected from the CSQ and CAQ to better understand the needs of caregivers in Texas. The SB 271 workgroup identified what changes will be made to DADS current intake processes to ensure sustained, ongoing data collection, and ongoing analysis of the profile of caregivers across Texas. DADS will identify regional differences in service availability; variances in need based on gender, age, care recipient conditions, and relationship; as well as the impacts of informal caregiving on employment and employers. Regularly updated data analysis of the profile of Texas caregivers will help to inform future policy and program decisions at DADS.

Procedures have been established for referring caregivers, identified through the CSQ process, to their respective local AAA. Beginning in fiscal year 2013, DADS regional intake staff will send follow-up resource letters to caregivers identified during the intake process who provide contact information in response to the CSQ. The resource letter will include a link to the **Take Time Texas** website, where they will have access to a searchable database of respite care providers across the state.

DADS formally launched the **Take Time Texas** website in May 2012. TakeTimeTexas.org, which was a result of SB 271 and House Bill 802 (81st Legislature, Regular Session, 2009) as well as a grant from the U.S. Administration on Aging, contains the "Texas Inventory of Respite Services," a searchable database of more than 900 respite care providers across the state. Although similar databases exist on a national level, the inventory is the first to create a comprehensive listing of Texas respite providers. Caregivers can search for providers in their area by name, county served, type of respite provided, age group served or the type of provider. TakeTimeTexas.org was created in partnership with the Texas Respite Coordination Center.

This website also provides a wide range of caregiver education and training materials, including self-assessment tools, information on identifying and managing stress related to caregiving, disease-specific information and educational programs. For service providers, the website offers an array of training and outreach materials.

From May through August 2012 the Texas Health and Human Services Commission conducted a survey of caregivers, as part of the grant requirements under the current Lifespan Respite Grant provided by the U.S. Administration on Aging. Data was collected with respect to caregiver demographics, care receiver relationship, caregiver tasks performed, awareness and use of respite and other caregiver support services. Caregivers across the state completed the survey on-line, through the **Take Time Texas** website, or in paper form, through surveys distributed by mail and by ADRCs and AAAs. A total of 2,649 responses were received from all parts of the state representing caregivers from a broader community base and not just those who were seeking services through DADS intake processes or AAAs.

- Preliminary data reveals one-half of respondents were female and the majority was between the ages of 40 and 70. The racial and ethnic distribution of caregivers approximated the state population with 49 percent White, 24 percent Hispanic, 11 percent Black/African American, 4 percent other (13 percent did not identify their race or ethnicity). Approximately 30 percent of caregivers were caring for an adult child, 23 percent were caring for a spouse or partner, 18.5 percent were caring for a parent and 11.8 percent were caring for a family member. Nearly one-half of the care recipients were age 70 or older.
- Caregivers perform an important role in helping older adults and persons with disabilities remain living at home by providing them with care and support. This was reflected in the survey responses, in which the primary tasks of caregivers were listed as transportation (82 percent), homemaking (82 percent), companionship or supervision (81 percent), healthcare assistance (74 percent), financial assistance (70 percent), and personal care assistance (63 percent).
- One important note is one-half of all respondents stated they spent 40 hours a week or more providing care. Research indicates “family caregivers who provide care 36 hours or more weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses, the rate is six times higher; for those caring for a parent the rate is twice as high.”<sup>16</sup> One quarter (25 percent) had been providing care for more than 10 years, 27 percent for 4-10 years and 28 percent for 1-3 years.
- The majority of caregivers (63 percent) responding to the survey knew what respite care was and two-thirds agreed respite care services reduced their stress level. Despite this, less than half (40 percent) had used respite services. One-half of respondents stated they did not know what type of respite care was available in their community and 67 percent did not know how to find a licensed and reputable provider. Only 37 percent had received help finding respite care services, with the majority of those (36 percent) obtaining help from a social service agency or AAA (33 percent). Caregivers also received help finding

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<sup>16</sup> Cannuscio, C.C., C Jones, C., Kawachi, I., G. A., Berkman, I., & Rimm, E. (2002). *Reverberation of Family Illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study*. American Journal of Public Health, 922 305-1311.

respite care from medical providers (24 percent), friends or family (23 percent), and ADRCs (15 percent).

HHSC expects to finalize its analysis of the caregiver survey by April 2013, at which time a final report and summary of the findings will be provided to DADS.

DADS Access and Intake division will regularly coordinate (at least annually) with program information technology (IT) staff to collect data from the DADS NTK system and SPURS. Regional needs will then be compared to resources available in the Inventory of Respite Services. This will allow DADS to identify gaps in services by region and/or zip code to better inform policy decisions, program focus, outreach activities and future infrastructure design.

Additionally, the Texas Lifespan Respite Care (TLRC) program will establish a plan with DADS Center for Policy and Innovation to perform ongoing data analysis to identify specific caregiver needs by region. DADS believes Texas experience in using electronic data and methods to assess caregivers and connect them to respite resources will help to inform the data collection and analysis processes of the larger network of lifespan respite care programs across the country. All evaluation components of this project will be focused on replication possibilities within this broader national context.

## Recommendations

1. Continue support for programs and services providing education, training, and awareness for caregivers including the **Take Time Texas** website and the Texas Inventory of Respite Services.
2. Continue support for respite services provided under the TLRC program. Family caregivers play a key role in providing support services which allow individuals to remain at home in their communities. In 2009, throughout the United States about 42.1 million family caregivers provided care to an adult with limitations in daily activities. It is estimated the value of the unpaid care provided by these caregivers was approximately \$450 billion. Texas caregivers provided 3,270,000 hours of care for an estimated value of \$34 billion<sup>17</sup>.
3. Promote expansion of consumer-directed and/or voucher models of service delivery. This allows caregivers to choose an individual provider that best meets their needs. This may also assist caregivers in rural counties where there are limited provider agency options. As reported in the *Health Affairs* Journal, “A shortage of well qualified, **reliable**, and affordable healthcare workers has a direct impact on the health and safety of persons with chronic conditions or disabilities. It also has a direct impact on the health and well-being of family

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<sup>17</sup> L. Feinbert, S. C. Reinhard, and R. Choula, *Valuing the Invaluable: 2011 Update, the Growing Contributions and Costs of Family Caregiving*, AARP Public Policy Institute Insight on the Issues 51 (Washington, DC: AARP, June 2011)

caregivers who must pick up the extra workload, which requires training and support they do not have, and which adds to their caregiving burden.”<sup>18</sup>

4. Continue support of services for caregivers and care recipients offered by DADS long-term services and supports and through AAAs, including caregiver information, education and training.
5. Expand access to supportive services and educational opportunities for caregivers through ADRCs. Examples of supportive services include, evidence-based care transitions support, options counseling, and evidence-based disease prevention and health promotion interventions. Some ADRCs also provide caregiver specific education and training with respect to personal care skills, caring for individuals with dementia and/or stress reduction.
6. Continue to provide a wide array of caregiver support services through the AAAs and TLRC program community partner organizations to address the broad range of assistance with tasks identified by caregivers. These include, respite, help with personal care tasks, homemaker chores, transportation, medication management, durable medical equipment, benefits counseling, emotional support and basic needs assistance (e.g., housing, meals, and utility assistance).
7. Implement a targeted outreach plan to educate “critical healthcare pathways” partners including, physician groups, hospital discharge planners, home health agencies and community-based organizations providing personal assistance services. Provide printed and on-line information about caregiver needs in addition to processes for referral to better coordinate medical and long-term care systems.
8. Disseminate findings of data analyses to stakeholders to support the development of effective local plans to serve caregivers.

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<sup>18</sup> Donelan, K., et al. (2002) Challenged To Care: Informal Caregivers in a Changing Health System. *Health Affairs*, July/August 2002, 222-231.