



# **A Profile of Informal Caregiving in Texas**

**As Required by  
Senate Bill 271, 81st Legislature, Regular Session, 2009**

**Texas Health and Human Services Commission  
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## 1. 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> Identifying and meeting the needs of the estimated 3.4 million caregivers in Texas<sup>2</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 United States, 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 giving and receiving care but also helps the state avoid long-term services and supports (LTSS) costs, which might otherwise be shifted to Medicaid. The economic value of caregiving by informal caregivers in Texas is estimated to be \$35.5 billion annually, with caregivers contributing over 3.2 billion hours of care.<sup>3</sup>

Between April 1, 2014, and March 31, 2016, the Health and Human Services Commission (HHSC) interviewed 12,729 informal caregivers from HHSC community services programs and area agencies on aging (AAA) programs. Informal caregivers who provide care to individuals seeking or receiving LTSS in Texas were included in the interviews. Hispanics were the predominant group of respondents caring for individuals interested in HHSC Medicaid and general revenue (GR) services; whereas non-Hispanic Whites were the largest group of caregivers who were assessed for caregiver services through the federal Older Americans Act (OAA) programs.

The data collected by HHSC provides further evidence relatives (most often spouses and children) are the primary informal caregivers 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 from primarily female children caring for parents, to older male spouses caring for their older female spouses.

In addition, HHSC found caregivers who are relatives of older individuals or persons with disabilities are more likely to live with their care recipient. Caregivers living with the care recipient reported higher stress levels than those who do not. Nine percent of caregivers reported no effective way to relieve their stress. Data also revealed the percentage of individuals living in the same household as their care recipients is higher for caregivers residing in urban areas than for those residing in rural areas. Only about eight percent of caregivers reported living 11 or more miles away from the individual for whom they provide care.

Approximately 33 percent of assessed caregivers were employed. Nearly 23 percent of informal caregivers were employed full-time and slightly over 10 percent of informal caregivers reported part-time employment. Informal caregivers reporting full-time or part-time employment were

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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 2014.

<sup>2</sup> AARP Public Policy Institute, *Valuing the Invaluable: 2015 Update*, 2015.

<sup>3</sup> AARP Public Policy Institute, *Valuing the Invaluable: 2015 Update*, 2015.

asked a variety of questions about the effects of caregiving on their employment. Most reported caregiving had no negative impacts on their employment, although those with full-time jobs reported higher stress levels than those employed part-time or not employed at all. A very small percentage reported having to quit a job in order to continue providing care. Less than one percent of caregivers expressed fear of losing their jobs.

This report reflects the progress HHSC and the State of Texas have made toward fully implementing direction given in Senate Bill (S.B.) 271, 81<sup>st</sup> Legislature, Regular Session, 2009. This includes identifying caregivers of individuals interested in accessing HHSC-administered Medicaid programs, establishing a standardized assessment to be used by the AAA to evaluate the needs of caregivers of individuals eligible to receive OAA services, and utilizing tools for the collection and analysis of data to allow for the formulation of an informal caregiver profile in Texas. A coordinated system involving 28 AAAs and 22 aging and disability resource centers (ADRCs) across all 11 HHSC regions worked to expand outreach and public awareness of services and supports available to assist informal caregivers statewide in preparing for and sustaining their caregiving roles. Through coordination of state programs, a mechanism was established to collect and create an inventory of respite services available statewide. In addition, an online resource was developed to assist caregivers in locating the services and supports available within their respective communities.

## 2. Introduction

As required by S.B. 271, HHSC developed this report on strategies implemented by the Texas Department of Aging & Disability Services (DADS) to collect and analyze data related to informal caregiver support services in Texas. In September 2010, DADS filed a report with the Office of the Governor and the Legislative Budget Board (LBB) required by the 2010-11 General Appropriations Act, S.B. 1, 81<sup>st</sup> Legislature, Regular Session, 2009 (Article II, Department of Aging and Disability Services, Rider 38) 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 at that time.

In response to S.B. 271, DADS filed a report in December 2012 titled *A Profile of Informal Caregiving in Texas*, (the title still in use today) and covered data collected from October 2010 through March 2012. The report focused on the demographics of informal caregivers and how services to these caregivers could be improved based on the expanded data collection. The 2014 report by the same name further detailed HHSC efforts to assist informal caregivers in long-term caring situations to prepare for and sustain their caregiving roles. The 2014 report focused on the analysis of collected data related to informal caregivers in Texas from February 2012 through March 2014<sup>4</sup>, and provided updated statistics, activities, and recommendations for the future support of caregivers in Texas.

The current *A Profile of Informal Caregiving in Texas* report focuses on expanded cross-tabulation of data to provide clear recommendations to further support caregivers statewide. This

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<sup>4</sup> Date range differs from 2012 report of October 5, 2010 through March 1, 2012. All future date ranges will be consistent to allow better data comparison.

updated report covers data collected from April 2014 through March 2016. The report should provide a clear and concise view of informal caregiving in Texas.

### 3. Background

In June 2009, Governor Rick Perry signed two pieces of legislation directing state agencies to identify caregivers and improve the delivery of caregiver support services in Texas: S.B. 271, relating to informal caregiver support services, and House Bill (H.B.) 802, 81<sup>st</sup> Legislature, Regular Session, 2009, relating to the creation of the lifespan respite care program. S.B. 271 incorporates recommendations<sup>5</sup> from the LBB to strengthen the delivery of informal caregiver supports, 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 an AAA
- Analyzing quantitative data collected from the caregiver status form and caregiver assessment form

DADS began activities in September 2009 with an initial focus on developing the required forms, known as the Caregiver Status Questionnaire (CSQ) (Appendix A) and the Caregiver Assessment Questionnaire (CAQ) (Appendix B). In October 2009, DADS met with 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, as appropriate, into the final version.

DADS shared information about S.B. 271 throughout the fall of 2009 with AAA directors and councils of governments. Additionally, agency staff met with the Texas Association of Area Agencies on Aging and the Texas Association of Regional Councils to discuss implementation of S.B. 271. In January 2010, a teleconference was held with AAA directors statewide, followed by the release of the CAQ draft to the AAAs for review. The comments and concerns resulting from the review were considered and incorporated, if appropriate, into the CAQ.

The CSQ and CAQ pilots were held in both rural and urban areas of Texas. In January 2010, a two-week pilot of the CSQ was performed in selected regional intake offices across the state (Regions 2, 6, 7, 8, and 9). A total of 134 caregivers participated in the limited pilot. 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. A total of 110 caregivers were assessed during the pilot.

The results of both pilots were reviewed and discussed with regional directors and AAA directors. Modifications resulting from comments received during pilot projects were

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

incorporated into the CSQ and the CAQ. 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.

In 2014, DADS applied the CSQ to informal caregivers of new applicants for community services 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) until September 1, 2014, 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 GR-funded services provided through DADS programs. The CSQ attempts to identify and collect information pertaining to the primary informal caregiver of an individual whose name is placed on a program interest list.

Completion of the CAQ occurs for all caregivers receiving AAA Caregiver Support Coordination funded through Title III-E of the OAA, also known as the National Family Caregiver Support Program. When an individual seeks help through an AAA, an information and referral specialist provides a variety of options for assistance based on regional community resources or resources offered directly by the AAA. When an eligible caregiver chooses to receive services offered by the AAA, the individual is referred to specialized caregiver supports staff for assistance as authorized by the OAA. The CAQ is administered to identify specific areas of need for the caregiver based on the caregiver's unique circumstances. Because the CAQ includes questions not included in the CSQ, discussion between the caregiver and AAA staff help to inform and develop a care plan based on documented need and consumer choice.

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 to ensure consistency of data. Some duplication of data is expected for consumers who completed the CSQ and who were then referred to an AAA for caregiver supports. It is possible caregivers referred by regional intake are not asked or may not choose to disclose the source of their referral when accessing services through the AAA. Currently, the CAQ and CSQ assessments include some of the same information for ease of data analysis; however, both assessments include program-specific data not included on the other program's assessment.

#### **4. 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 may act as the main point of contact for coordination of care between physicians, home health providers, and other health care professionals seeking to gain information about the individual. Caregivers may play a vital role in the development of a service plan to meet the individual's needs, and help coordinate health care and supportive services. The caregiver is an invaluable asset. Often, the availability of a caregiver is the link that enables the individual to continue living in their own home and remain part of their community, avoiding institutional placement and potentially higher costs. Sustaining and supporting informal caregivers should continue to be a primary topic for future policy and practice discussions.

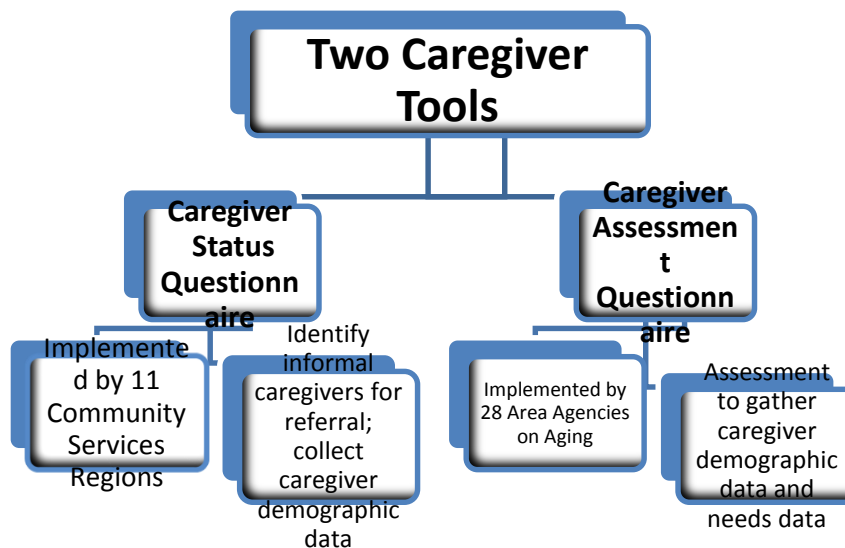
According to S.B. 271, HHSC will collect and analyze data to:

- 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
- 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 HHSC community services programs, including CCAD, Medically Dependent Children's Program, and IHFS. The CSQ is administered over the phone to identify and collect information pertaining to the primary informal caregiver of the individual whose name is placed on a program interest list or who has applied for specific community services programs. Staff is not required to complete a CSQ for anyone other than the primary informal caregiver. The questions from the CSQ allow HHSC to gain a demographic profile of the caregiver without thoroughly assessing the needs of the caregiver. It is also used to refer people who may qualify for services provided through the OAA to the AAAs for further assessment.

Completion of the CAQ occurs for all caregivers receiving 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 and based on the preferences of the caregiver and the care recipient.



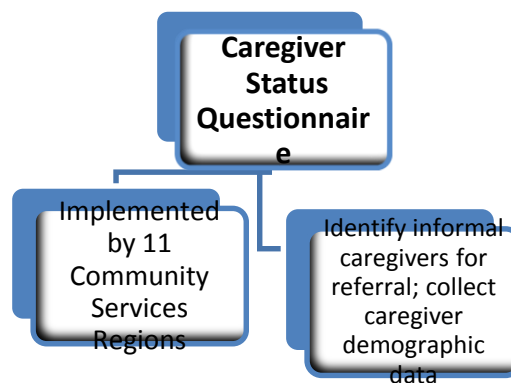
While some AAAs previously developed and were using assessments for services under the National Family Caregiver Support Program of the OAA, no single assessment of needs for caregivers had been developed for consistent use across the state. Neither the CSQ nor the CAQ has the capability of assigning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

HHSC 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, employment issues and stress/burden measurement tools.

State staff worked with stakeholder groups to review and respond to the final draft of the CAQ and the CSQ. Every question on each tool was reviewed for clarity, content, language and format. The protocol for administering each tool and the quality of the questions to produce reliable analytical data was also evaluated. The project launched in August 2010.

#### *CSQ In-depth*

The CSQ was developed to identify and collect information pertaining to primary informal caregivers in response to the S.B. 271 requirement to implement a caregiver status form into the existing Medicaid process. The purpose of the questionnaire is to identify informal caregivers for referrals to appropriate support services and to develop a profile of caregivers. 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. The questions are designed to provide HHSC with a demographic profile of the caregiver and are not intended to assess the caregiver's full range of needs, although the CSQ may identify some needs that would benefit from a referral to the local AAA or other area resources.



Eligibility screening criteria for AAA services included in the CSQ are:

- 60 years of age or older and caring for an individual of any age

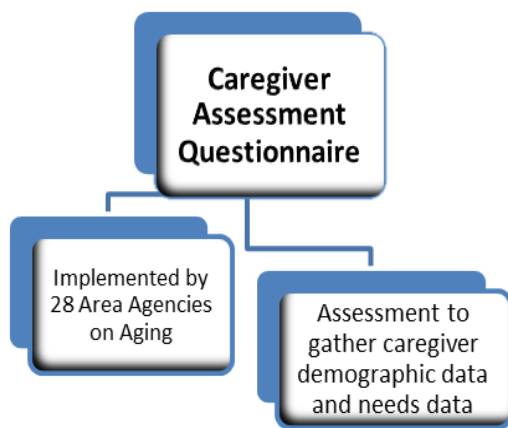
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<sup>6</sup> The risk for institutionalization for the care receiver that can result from challenges of caregiving.



- 55 years of age, an older relative, and meets one of the following criteria:
  - Is caring for a child under the age of 18 in his/her home because the biological or adoptive parents are unable or unwilling
  - Has legal custody or guardianship or is raising the child informally; or is caring for a recipient age 19-59 with severe disabilities
  - Is caring for an individual of any age with Alzheimer’s disease or dementia

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



*CAQ In-depth*

The CAQ was developed in response to the S.B. 271 requirement to standardize a caregiver assessment and protocol for caregivers accessing services through an AAA. The CAQ incorporates the questions used in the CSQ and includes additional questions to develop a profile of Texas caregivers.

A CAQ is completed for all caregivers receiving Caregiver Support Coordination funded through Title III-E of the OAA. Results of the CAQ are used to develop an individual plan of care, as appropriate, taking into consideration the preferences of the caregiver and care recipient.

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>7</sup> An older relative caregiver is defined as “a grandparent, step-grandparent or other older relative 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>8</sup>

As a result of S.B. 271, the 28 AAAs in Texas have used the CAQ to consistently assess caregiver needs since 2010. Developed as an assessment tool for caregivers who meet the eligibility criteria as defined by the OAA and are seeking help through AAAs, the CAQ assists AAA staff to identify needs and services for caregivers accessing services. When appropriate, the AAA develops an individual plan of care based on needs identified through the assessment.

<sup>7</sup> Older Americans Act, as amended in 2016, 42 U.S.C. §3022.

<sup>8</sup> Older Americans Act, as amended in 2016, 42 U.S.C. §3030.

The CAQ identifies areas in which a caregiver may need education or training to enhance knowledge and skills needed. The assessment guides the professional conducting the CAQ to help the caregiver understand how a more family-centered approach to caregiving can be achieved. The CAQ also includes questions addressing the caregiver's physical and mental health status.

Following the initial implementation phase, five randomly selected AAAs were asked if the assessment had resulted in any positive, unexpected outcomes. Some AAAs reported the process greatly assisted in care planning, but more importantly, AAAs reported the assessment 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. Also, the caregivers perceive for the first time, interest in the individual as a person needing assistance.

The CAQ data collected are entered into the statewide-automated data system. This data is used to identify caregivers meeting the OAA priority populations and to identify target populations for outreach and public awareness efforts. Resulting data may be individually analyzed by an AAA for service planning purposes. The caregiver seeking services through the AAA may choose to not identify the source of their referral; therefore, some duplication of data can result for individuals who completed the CSQ and subsequently referred to an AAA by the regional intake office.

An individual, or another person 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 targeting 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 HHSC when this mandate was initiated. Information gathered is entered into the State Unit on Aging Programs Uniform Reporting System (SPURS) using a specialized data entry format.

## **5. Data Analysis**

Between April 1, 2014, and March 31, 2016, HHSC interviewed 12,728 informal caregivers from HHSC community services programs and AAA programs providing care to individuals seeking or receiving LTSS in Texas.

The data analysis section profiles the characteristics of caregivers responding to the CSQ and CAQ. Respondents to the CSQ were informal caregivers of new applicants for CCAD, CBA (until September 1, 2014), 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**



The 6,985 caregivers who responded to the CSQ between April 1, 2014, and March 31, 2016, represented 222 of the 254 Texas counties. The following counties experienced the highest number of caregiver calls:

- 1,108 callers – Harris County
- 918 callers – Bexar County
- 531 callers – Dallas County
- 327 callers – Tarrant County

The Office of Management and Budget (OMB)<sup>9</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 found to reside in urban counties than in rural counties.. Of those caregivers who spoke with HHSC, 5,420 lived in 81 urban counties while 866 lived in 141 rural counties. Another 699 caregivers do not live in urban or rural counties as defined by OMB.

Caregivers reside in all 11 Health and Human Services (HHS) regions. Regions 3, 6, 7, and 8 accounted for 79 percent of all calls. Regions 3, 6, and 8 all had over 1,000 callers each accounting for 66 percent of callers, while Regions 1, 2, 4, 5, 7, 9, 10, and 11 accounted for 34 percent of callers.

The 5,743 caregivers who completed the CAQ represented 202 Texas counties across the state. The top six counties to have caregivers complete the assessment were Tarrant, Dallas, El Paso, Bexar, Harris and Colin. These counties represented the highest number of caregiver assessments completed. The number of caregivers assessed by county included:

- 483 residing in Tarrant County (Tarrant County AAA)
- 334 residing in Dallas County (Dallas County AAA)
- 317 residing in El Paso County (Rio Grande AAA)
- 284 residing in Bexar County (Bexar County AAA)
- 232 residing in Harris County (Harris County AAA)
- 178 residing in Collin County (North Central Texas AAA)

The CAQ is only required when the caregiver receives support coordination. The number of assessments for each area was not representative of the ratio of the older population (60 and over) living in metropolitan or rural areas of the state.

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<sup>9</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 which are not part of a Metropolitan Statistical Area (MSA) are considered rural. Micropolitan counties are considered non-Metropolitan or rural along with all counties which 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/>.

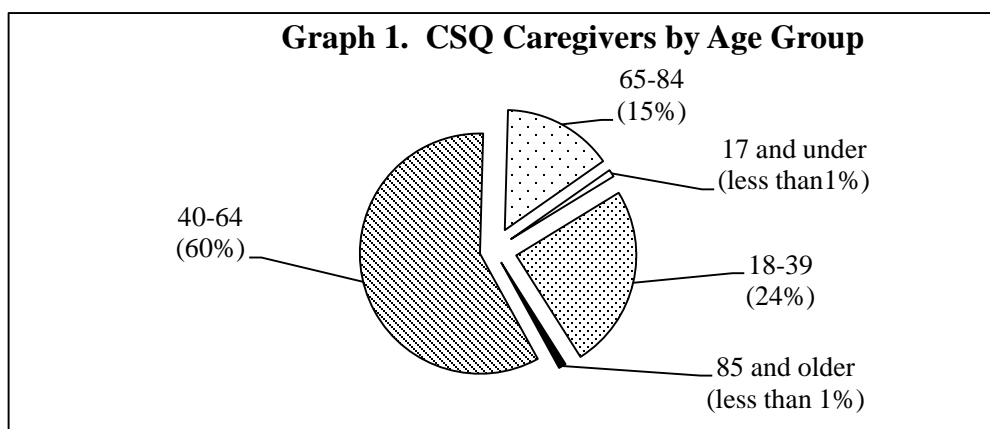
Seventy-one percent of caregivers assessed were not aware of caregiver support services prior to contacting the AAA for assistance.

## Demographic Characteristics of Caregivers

In 2016, Hispanics were the predominant group of caregivers (38 percent) among CSQ respondents. The next largest group consisted of non-Hispanic Whites (36 percent) followed by Blacks/African Americans (25 percent). Asians, American Indian/Alaskan Native and Native Hawaiian/Other Pacific Islanders made up the remaining one percent of the respondents.

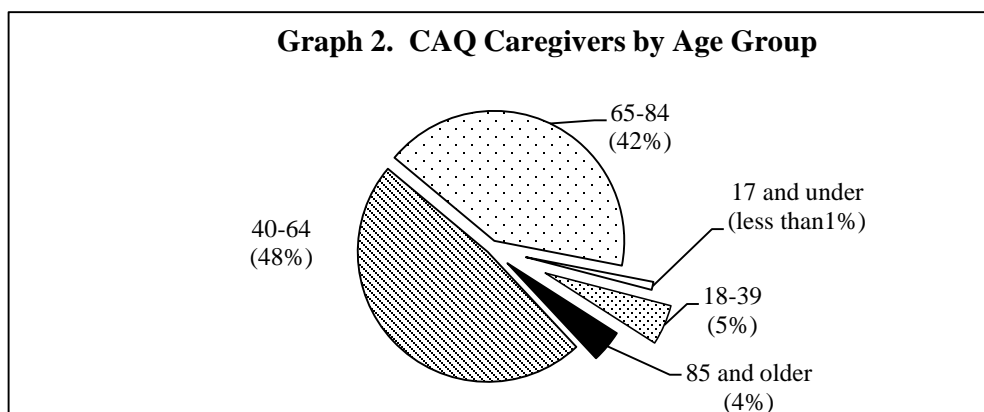
The majority of caregivers assessed with the CAQ by AAAs were non-Hispanic White (49 percent), with the next largest group reporting to be of Hispanic origin (30 percent), followed by Black/African American (18 percent). Asians represented one percent of caregivers assessed, with American Indian/Alaskan Native and Native Hawaiian/Other Pacific Islander comprising the remaining three percent.

As the “CSQ Caregivers by Age Group” pie chart<sup>10</sup> shows in Graph 1 below, the majority of caregivers were between the ages of 40 and 64, making up 60 percent of CSQ respondents. Caregivers between the ages of 18 and 39 made up the next largest group at 24 percent, followed by caregivers between 65 and 84 years of age at 15 percent. The remaining one percent of caregivers were either 17 and under or were 85 and older.



As was the case with the CSQ, the pie chart for the “CAQ Caregivers by Age Group” in Graph 2 reveals the majority of caregivers assessed were between the ages of 40 and 64, comprising 48 percent. Caregivers between the ages of 65 and 84 comprised the next largest group at 42 percent, followed by caregivers between 18 and 39 years of age at five percent. Less than one percent of caregivers were 17 and under and four percent were 85 and older.

<sup>10</sup> Age ranges for this report differ slightly from the 2012 report to follow the standard across HHSC for reporting data.



The CAQ also includes questions about level of poverty. The younger the caregiver, the more likely the caregiver was to be in poverty. Among caregivers age 18-39, 34 percent reported being in poverty. For caregivers who are age 40-64, there is a significant drop in the rate of poverty (27 percent), followed by caregivers 65-84 years old (21 percent). Caregivers age 85 and older reported 15 percent living in poverty. Women were slightly more likely to report living in poverty than men, 26 percent versus 21 percent respectively. The ratio between women living in poverty to the number of men living in poverty remains similar for 2012 and 2014.

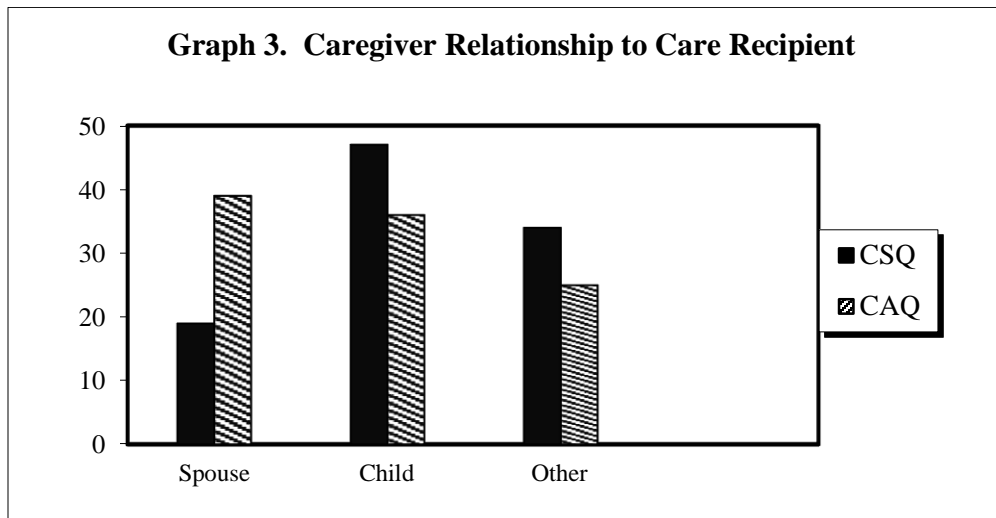
Similar to the 2012 and 2014 results, 71 percent of caregivers assessed through the CAQ were female, with females representing the majority in all age groups. This figure is lower than the 80 percent of female caregivers responding to the CSQ. The ratio of female to male caregivers decreased slightly as the age group increased. Of the total caregivers who were male, the largest portion was represented in the 65-84 age groups. This declining ratio may be attributed in part to a shift in focus of caregiving from primarily female children caring for parents, to older male spouses caring for their female spouse.

### Caregivers and Relationship to Care Recipient

Data shows primary informal caregivers were most often relatives of the care recipients. The majority of caregivers were children or spouses of the care recipients. The data reflected 30 percent of men were more likely to be the spouse of their care recipient while 48 percent of women were more likely to care for a parent. It is important to note differences exist between questions for percentages of children and spouses providing care. Spouses represented 19 percent of CSQ respondents and 39 percent of caregivers responding to the CAQ. This fact may indicate the state is reaching broader cohorts of caregivers. Children of the care recipient represented 36 percent of the CAQ data and 47 percent of the CSQ data.

On the CAQ, other relatives, including sons and daughters-in-law, grandchildren, grandparents, and siblings accounted for 21 percent of all caregivers. Friends, neighbors, and other non-relatives accounted for fewer than four percent of caregivers. On the CSQ, 10 percent were other relatives to the care recipient, while grandchildren, grandparents, life partners, or siblings made up 12 percent of caregivers. 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 (nine percent), served as caregivers as reported in the CSQ.



### Caregivers' Family Composition

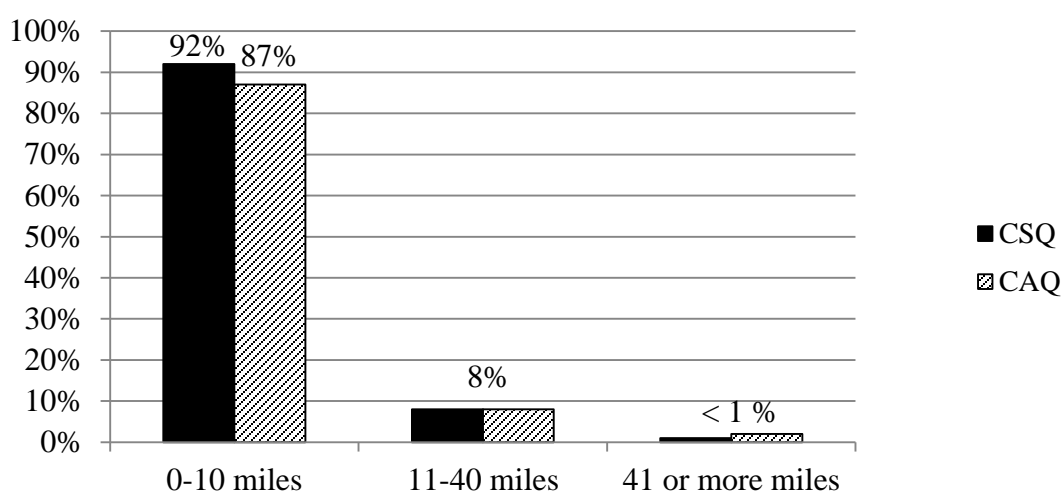
Most respondents to the CAQ reported being married (68 percent), and 86 percent of them indicated they did not have children under the age of 18. The composition of caregivers responding to the CSQ differed: 51 percent reported not being married and 74 percent indicated they did not have children under the age of 18.

Of the CAQ respondents, 24 percent of Asians, 21 percent of Hispanics, 21 percent of Black/African Americans, and 21 percent of non-Hispanic Whites indicated they did not have children under the age of 18. The CSQ data indicated Hispanics (30 percent) and Asians (30 percent) were more likely to indicate having children under the age of 18. Furthermore, 26 percent of Blacks/African Americans, 21 percent of non-Hispanic Whites, and 22 percent of American Indian/Alaskan Native and Native Hawaiian/Other Pacific Islanders reported having children under age 18.

### Proximity of the Caregiver to the Care Recipient

Regardless of race/ethnicity, most caregivers reported living with their care recipient (76 percent for both the CSQ and CAQ). On the CSQ, a slightly higher proportion of urban caregivers (75 percent), as compared to rural caregivers (74 percent), reported living with the care recipient. The majority, 92 percent (CSQ) and 87 percent (CAQ) of caregivers lived within 10 miles of the care recipient regardless of age or race/ethnicity.

**Graph 4. Proximity to Care Recipient**



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

According to CSQ data, 97 percent of caregivers were not paid to provide care to the recipient, regardless of race/ethnicity. Seventy-seven percent of caregivers indicated they were the only non-paid caregiver for the care recipient. In addition, a small percentage of paid caregivers did indicate they were seeking services by completing the CSQ.

According to CAQ data, 98 percent of the caregivers were non-paid.<sup>11</sup> Sixty-six percent reported being the only non-paid person providing care to the care recipient as compared to 77 percent of CSQ respondents. In addition, a small percentage of paid caregivers did indicate they were seeking services by completing the CAQ.

### **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 of caregivers, 99 percent, provided care at least once per week, regardless of race or ethnicity. Slightly less than one percent assisted the care recipient monthly. On the CSQ, 94 percent of caregivers reported providing care every day. About five percent provided care weekly, and less than one percent provided care monthly or less. Most caregivers had someone to call on in an emergency, as reported on the CAQ (83 percent) and CSQ (56 percent), while 17 percent of CAQ and 44 percent of CSQ respondents reported having no other person to call in case of emergency.

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

CSQ data also indicated the amount of time caregivers had been providing care. Caregivers providing care between one month and one year at the time of their interview made up 30 percent of respondents. Caregivers who had been providing care between one and two years made up 16 percent. While 27 percent of caregivers had been providing care between two and five years and some had been providing care between five and 10 years (14 percent), 12 percent had been providing care for 10 years or more. Less than two percent reported providing care for less than one month.

## Effects of Caregiving on Employment

Over half of caregivers indicated they were not employed on both the CSQ (69 percent) and CAQ (65 percent). Approximately 20 percent of CSQ respondents and 26 percent of CAQ respondents were employed full-time, while 11 percent of CSQ and 10 percent of CAQ respondents were employed part-time. Caregivers who reported caregiving had an impact on their employment were asked a variety of questions. According to the CSQ findings, caregivers reported few negative impacts on their employment as a result of providing care to another person. For caregivers whose responsibilities affected their employment, eight percent reported they had quit work, one percent reported they had changed work schedules, two percent reported losing wages or having a period with no income, and five percent reported they take leave frequently.

The Families and Work Institute reports in *The Eldercare Study: Everyday Realities and Wishes for Change*, “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, 30 percent of caregivers with employment reported caregiving responsibilities have affected their work. Reported impacts to jobs included decreasing work hours or going part-time, losing wages or utilizing extended leave without pay, and difficulty focusing or concentrating at work.

With regard to race and ethnicity from the CSQ findings, three percent of non-Hispanic Whites, three percent of Hispanics, and two percent of Blacks/African Americans reported to have lost wages or to have experienced periods with no income due to caregiving responsibilities. Hispanics, non-Hispanic Whites, and Blacks/African Americans were equally inclined to take leave frequently because of caregiving responsibilities (5 percent each).

By race or ethnicity from the CAQ findings, Asians were more likely to report being employed full-time, at 38 percent. Twenty-nine percent of Black/African Americans, 30 percent of Hispanics, and 22 percent of non-Hispanic Whites worked full-time. Sixty-five percent of caregivers reported they currently do not work. Seventy-eight percent of non-Hispanic Whites, 70 percent of Hispanics, and 70 percent of Blacks/African Americans assessed do not work either full-time or part-time. Forty-eight percent of Asians are unemployed.

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<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).



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 to part-time.”<sup>13</sup> The CSQ and CAQ do not collect data regarding whether the employed caregiver’s work environment allows or does not allow flexible schedules in order to provide care. The CSQ and CAQ data on employment may, in part, reflect 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**

The health status of caregivers has an impact on their ability to provide care, regardless of race or ethnicity. Fewer caregivers (22 percent) reported on the CSQ as having had a chronic health condition or having experienced a recent health crisis, as compared to 45 percent of caregivers responding to the CAQ. More than half (53 percent) of those who had a chronic health condition or a recent health crisis indicated their health condition affected their ability to provide care. Of the CAQ respondents, 34 percent stated their health has affected their ability to provide care for the care recipient.

## **Stress Level of Caregivers**

The majority of caregivers responding to both the CSQ and CAQ reported caregiving as stressful. It is important to pay attention to caregiver stress. 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> Forty-seven percent of caregivers reporting on the CSQ found caregiving to be stressful. Of those who found caregiving to be stressful, 46 percent rated their stress level as moderate. Thirty-two percent said their stress level was high, and 22 percent of respondents indicated their stress level was low.

CAQ data tells us 78 percent of caregivers find caregiving to be stressful, with 28 percent of those caregivers reporting their stress level as high. CSQ data was somewhat lower, 41 percent of caregivers who found caregiving to be stressful reported only moderate stress levels, and 29 percent reported low stress levels.

According to CAQ findings, caregivers were responsive to questions about the impact of caregiving on their stress levels. Ninety percent of caregivers reported they agreed or strongly agreed with feeling a sense of satisfaction helping the care recipient and 84 percent reported feeling confident about providing care. Sixty-five percent of caregivers agreed or strongly agreed

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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.

providing care while meeting other family and work responsibilities was stressful and 87 percent of caregivers felt they had an obligation to provide care to the care recipient. Also, 31 percent of caregivers reported they could do a better job of providing care than someone else could.

Forty-one percent reported agreeing or strongly agreeing their finances are strained due to providing care. Overall, non-Hispanic Whites most frequently reported their finances were strained because of caregiving. Financial strain was reported by 41 percent of non-Hispanic Whites, 34 percent of Asians, 34 percent of Hispanics, and 26 percent of Blacks/African Americans.

According to the CAQ findings, regardless of race, the majority of caregivers feel some sense of satisfaction in providing care for another person. While 61 percent reported engaging in activities which effectively relieve stress, 30 percent reported activities “somewhat” relieve stress and nine percent reported finding no effective ways to relieve stress. Sixteen percent indicated they would like information, education, and/or training about caring for oneself while providing care for others.

#### *Stress and Proximity to Care Recipient*

Caregivers who reported not living with the care recipient reported slightly lower stress levels than those who reported living with the care recipient, as reported on both the CSQ and CAQ. Among CSQ caregiver respondents who live with the care recipient, 33 percent reported high stress levels, 46 percent reported stress levels as moderate, and 21 percent reported low stress levels. Among those who did not live with the care recipient, 25 percent reported high levels of stress, while 48 percent reported stress levels as moderate, and 28 percent reported low stress levels. Similar to the CSQ findings, CAQ findings indicated 29 percent of caregivers who reported living with the care recipient rated their stress level as high, versus 22 percent of those who did not live with the care recipient.

CAQ data revealed stress levels are relatively consistent when a caregiver lives within 100 miles of the care recipient. High stress levels were reported by 28 percent of caregivers living within 10 miles of the care recipient, 24 percent of those living 11 to 40 miles from the care recipient, and 27 percent living 41 to 100 miles away.

#### *Stress Level of Employed Caregivers*

Caregivers reported various stressors while working full-time. On the CSQ, caregivers with full-time jobs were more likely to report moderate stress levels than those who were employed part-time or not employed at all. Of those caregivers employed full-time, 30 percent reported high stress levels, and 52 percent reported moderate stress levels. Of those employed part-time, 33 percent reported high stress levels, and 38 percent reported moderate stress levels. Of those caregivers who were not employed, 32 percent reported high stress levels and 45 percent reported moderate stress levels.

Twenty-six percent of caregivers responding to the CAQ reported working full-time. Of those, 32 percent reported feeling they could do a better job of caring for the care recipient than

someone else. Of the nine percent of caregivers working part-time, 30 percent of those respondents reported feeling they could do a better job of caring for the care recipient. Variances in stress levels for employed versus non-employed caregivers continue to be insignificant based on the 2012 and 2014 reports. Most (65 percent) of the caregivers assessed using the CAQ were not employed.

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

The majority of caregivers reported on the CSQ and CAQ they were not providing care to more than one recipient. On the CSQ, 81 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, 37 percent reported high stress levels, as compared to 30 percent of those who provide care to only one care recipient.

Of all caregivers surveyed through the CAQ, 82 percent reported they were not caring for more than one person, about the same as those responding to the CSQ. Of those who were providing care for more than one person, 31 percent reported high stress. Twenty-five percent reported high stress when caring for only one person. Data revealed a significant variance in stress when providing care to more than one person when compared to providing care to one person.

**CAQ Support Tasks Performed by Caregivers**

A high percentage of caregivers provide significant assistance when taking care of another person. Most caregivers (85 percent) reported helping the care recipient with homemaker chores. Homemaker chores include performance of housekeeping and home management to help the recipient sustain independent living in a safe and healthful home environment. Almost three-fourths (72 percent) of caregivers performed such support tasks as personal care. Personal care is assisting older individuals that have difficulty performing activities of daily living, such as bathing and grooming. Nearly all caregivers reported helping the care recipient with health care (doctor visits, medication monitoring).

**Support Tasks Provided**

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

Caregivers reported a high level of responsibility in taking care of the recipient. Ninety-one percent reported the care recipient requires assistance with three or more personal care tasks. Three percent reported being a grandparent or older relative, age 55 and older, providing care for children with severe disabilities. Almost half (43 percent) reported the care recipient has Alzheimer’s disease or related dementia. With 39 percent of care recipients having been hospitalized recently, and nine percent of caregivers reporting a recent hospitalization for themselves, it is not surprising 28 percent of caregivers reported the care recipient is at risk of institutionalization.

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

Most caregivers (71 percent) were not aware of support services prior to contacting the AAA, and 78 percent had not received caregiver support services in the past. Eight percent of caregivers reported reluctance to accepting outside help. Four percent of caregivers expressed lack of trust of service providers in the home and eight percent believed no one else could provide care as well as they do. Thirty-one percent had other concerns about receiving caregiver support. These concerns persisted even though 95 percent reported their caregiving is likely to continue indefinitely.

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

More than half of caregivers (63 percent) indicated they felt “very” knowledgeable about the care recipient’s disease or condition. Thirty-five percent reported feeling “somewhat” knowledgeable and three percent reported feeling “not at all” knowledgeable about the care recipient’s disease or condition. Percentages on the chart below indicate caregivers who reported they would like information, education, or training for specific topics.

**Information, Education, or Training**

<b>Percentage of Caregivers Wanting More Information</b>	<b>Topics</b>
24	In-home support services
13	Support groups
13	How to provide care to an aging individual
12	Home safety and/or home modifications or equipment
11	Care recipient’s disease or condition
11	Long-term care options (e.g., 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	How to choose a long-term care facility
5	Hands-on skills training for personal care tasks (e.g., bathing, grooming, etc.)

Percentage of Caregivers Wanting More Information	Topics
5	Short-term respite care in a facility

More than half (55 percent) of those with “no knowledge” or “some knowledge” of the care recipient’s condition reported a high stress level. Those with “a lot of knowledge” of the care recipient’s condition (30 percent) were the least likely to report high stress.

Sixty-one percent of caregivers reported engaging in activities which effectively relieve stress; however, 30 percent reported their activities were “somewhat” effective at relieving stress, and nine percent reported finding no effective ways to relieve their stress.

## 6. Conclusions

- Most caregivers assessed were between the ages of 40 to 64 years.
  - For the CSQ, the next largest group of caregivers was between the ages of 18 and 39.
  - For the CAQ, the next largest group of caregivers was between the ages of 65-84.
- Compared to the 2014 report, there was a significant drop in the CSQ data for the percentage of caregivers who reported caring for spouses; this may indicate the state is reaching broader cohorts of caregivers.
- The majority of caregivers were female, but the ratio of female to male caregivers decreases as age increases.
- The majority of caregivers were children or spouses of the care recipient.
- Married relatives had primary responsibility for caregiving to care recipients with whom they resided. A slight majority of caregivers assessed using the CSQ were not married.
- Most caregivers lived with the care recipient and were the only non-paid caregiver.
- 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. Caregivers living with the care recipient reported slightly higher stress levels than those who reported not living with the care recipient.
- Nine percent of caregivers found no effective way to relieve stress, a one percent increase compared to the 2014 report.
- Caregiver knowledge about a care recipient’s condition appeared to reduce stress.
- Caregiving responsibilities negatively affected the work of over one-third of employed caregivers. An average of 64 percent of respondents said their caregiver responsibilities had not affected their employment. For those whose employment was affected, a small percentage reported taking leave frequently due to caregiving responsibilities.
- Most caregivers felt caregiving would continue indefinitely, with almost half believing the care recipient was at risk of institutionalization. Only five percent requested information about choosing a long term care facility, but 24 percent sought information about in-home services.
- Most caregivers were willing to accept help from others and a majority of caregivers could call on someone to help in an emergency.

- Caregivers were highly likely to assist a care recipient in a multitude of essential life activities.
- Caregivers most frequently requested information about in-home support services, support groups, home safety and home modification, and caring for an aging individual.
- Almost half of all caregivers assessed by the AAA were caring for an individual with Alzheimer's disease.

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

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 began sending follow-up resource letters to caregivers identified during the intake process who provide contact information in response to the CSQ. The resource letter includes a link to a searchable database of respite care providers across the state, known as the Take Time Texas website.

DADS formally launched the Take Time Texas website in May 2012. TakeTimeTexas.org is a result of S.B. 271 and H.B. 802 from the 81<sup>st</sup> legislature and a grant from the U.S. Administration on Aging. The Take Time Texas website hosts an inventory of respite services in Texas, which includes a searchable database of more than 900 respite care providers across the state. Although similar databases exist on a national level, this 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.

The Take Time Texas 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.

HHSC Access and Eligibility Services staff has taken measures to increase awareness of the Take Time Texas website by launching outreach efforts. Staff is also working to expand the inventory of respite services, allowing more caregivers to find services in their communities.

HHSC enhanced the Take Time Texas website to increase user interaction, awareness of the Take Time Texas website, average time spent on the website, the amount and accuracy of respite provider information and to make the site more user friendly overall.

HHSC Access and Eligibility Services will regularly coordinate with program information technology staff to collect data from the NTK system and SPURS. Regional needs will then be

compared to resources available in the inventory of respite services. This will allow HHSC to identify gaps in services by region or zip code to better govern policy decisions, program focus, outreach activities, and future infrastructure design.

## 7. Recommendations

- 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.
- Continue support for respite services provided under the Texas Lifespan Respite Care (TLRC) program. Family caregivers play a key role in providing support services, which allow individuals to remain at home in their communities. Nationally, in 2013, about 40 million family caregivers in the United States provided an estimated 37 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion in 2013.<sup>16</sup>
- Promote expansion of consumer-directed and/or voucher models of service delivery. These models allow caregivers to choose an individual provider to best meet 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 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>17</sup>
- Continue support of services for caregivers and care recipients offered by HHSC LTSS and AAAs, including caregiver information, education, training, and support services, such as home modifications and short-term respite.
- Expand access to support services and educational opportunities for caregivers through the ADRCs. Examples of support 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 stress reduction.
- 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).
- Promote increased caregiver access to “hands-on” practical training opportunities. This training should include enhanced communication, training, and curricula which support caregivers who provide complex care such as medication management and wound care for adults with multiple chronic conditions.

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<sup>16</sup> AARP Public Policy Institute (July 2015). Valuing the Invaluable: 2015 Update- Undeniable Progress, but BIG Gaps Remain.

<sup>17</sup> Donelan, K., et al. (2002) Challenged To Care: Informal Caregivers in a Changing Health System. *Health Affairs*, July/August 2002, 222-231.

- Implement a targeted outreach plan to identify and partner with faith-based and volunteer organizations to expand the number of free respite programs available in the state.
- 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.
- Disseminate findings of data analyses to stakeholders to support the development of effective local plans to serve caregivers.



## List of Acronyms

<b>Acronym</b>	<b>Full Name</b>
AAA	Area Agency on Aging
ADRC	Aging and Disability Resource Center
CAQ	Caregiver Assessment Questionnaire
CBA	Community Based Alternatives
CCAD	Community Care for the Aged and Disabled
CSQ	Caregiver Status Questionnaire
DADS	Texas Department of Aging & Disability Services
GR	General Revenue
H.B.	House Bill
HHSC	Health and Human Services Commission
IHFS	In-Home and Family Support
LTSS	Long-term Services and Supports
NTK	Automated Intake
OAA	Older Americans Act
OMB	Office of Management and Budget
S.B.	Senate Bill
SPURS	State Unit on Aging Programs Uniform Reporting System
TLRC	Texas Lifespan Respite Care



<b>Caregiver's Name:</b>		<b>Date:</b>		
<b>Care Recipient's Name:</b>				
25. Are you employed?		<input type="checkbox"/> Full-time	<input type="checkbox"/> Part-time	<input type="checkbox"/> Not Employed
26. Have your caregiver responsibilities ever affected your employment?		<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Refused to Answer
(If No, go to question 28)				
27. How has your employment been affected? (Select all that apply)				
<b>Schedule</b>	<b>Pay</b>	<b>Leave</b>	<b>Work Relationships</b>	<b>Performance</b>
<input type="checkbox"/> Changed jobs	<input type="checkbox"/> Has taken a second job	<input type="checkbox"/> Takes leave frequently	<input type="checkbox"/> Feeling of isolation	<input type="checkbox"/> Decreased confidence in own ability
<input type="checkbox"/> Decreased hours or went part-time	<input type="checkbox"/> Has lost wages or periods with no income	<input type="checkbox"/> Used all paid leave; no leave remaining	<input type="checkbox"/> Less co-worker interaction	<input type="checkbox"/> Decrease in productivity
<input type="checkbox"/> Has taken extended leave with pay	<input type="checkbox"/> Has taken leave without pay (LWOP)	<input type="checkbox"/> Exceeded Family Medical Leave Act (FMLA)	<input type="checkbox"/> Tension or problem with co-worker	<input type="checkbox"/> Difficulty with concentration or focus
<input type="checkbox"/> Quit job	<input type="checkbox"/> Missed promotion opportunity		<input type="checkbox"/> Tension or problem with supervisor	<input type="checkbox"/> Fear of losing job
	<input type="checkbox"/> Received pay cut or pay decreased			<input type="checkbox"/> Perform or manage caregiver tasks at work
<b>Caregiver Skills and Training Assessment</b>				
28. Which of the following tasks do you assist the care recipient with? (Check all that apply)				
<input type="checkbox"/> Personal care tasks (ADLs)	<input type="checkbox"/> Health care (doctor visits, medication monitoring)			
<input type="checkbox"/> Homemaker chores (IADLs)	<input type="checkbox"/> Supervision			
<input type="checkbox"/> Transportation	<input type="checkbox"/> Emotional support			
<input type="checkbox"/> Managing finances	<input type="checkbox"/> 29. Other (describe):			
30. If [care recipient's name] has a chronic disease or condition, how knowledgeable do you feel about this disease or condition? Care recipient's disease/condition:				
<input type="checkbox"/> Very <input type="checkbox"/> Somewhat <input type="checkbox"/> Not at all				
31. Do you need information, education and/or training about the following? (Check all that apply)				
<input type="checkbox"/> How to care for yourself while caring for others	<input type="checkbox"/> In-home support services			
<input type="checkbox"/> How to provide care to an aging individual	<input type="checkbox"/> Short-term respite care in a facility			
<input type="checkbox"/> More information about care recipient's disease/condition	<input type="checkbox"/> Choosing a long-term care facility			
<input type="checkbox"/> How to get other family members to help	<input type="checkbox"/> Support groups			
<input type="checkbox"/> Home safety and/or home modifications, or equipment	<input type="checkbox"/> Individual counseling options			
<input type="checkbox"/> Legal and financial issues, powers of attorney, living will	<input type="checkbox"/> On-line information and supports			
<input type="checkbox"/> Long-term care options (insurance and/or other benefits)	<input type="checkbox"/> Hands on skills training for personal care tasks (bathing, grooming, toileting)			
32. <input type="checkbox"/> Other, please describe:				

<b>Caregiver's Name:</b>		<b>Date:</b>				
<b>Care Recipient's Name:</b>						
<b>Caregiver Stress Interview</b>						
33. Do you find caring for [care recipient's name] to be stressful?						<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to Answer
34. Would you rate your stress level as:		<input type="checkbox"/> Low	<input type="checkbox"/> Moderate	<input type="checkbox"/> High	<input type="checkbox"/> Refused to Answer	
<b>Check the response that best describes how you feel:</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>	<b>Refused to Answer</b>
35. I feel a sense of satisfaction helping [care recipient's name].	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. I am confident about providing care to [care recipient's name].	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Caring for [care recipient's name] while trying to meet other responsibilities for my family or work is causing increased stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I feel a sense of obligation to provide care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. My health has suffered because of my involvement with providing care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. My finances are strained because I provide care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I could do a better job of caring for [care recipient's name].	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. What do you do to cope with the stress related to the challenges of caregiving? Describe:						
43. Is this working to help relieve stress?		<input type="checkbox"/> Yes	<input type="checkbox"/> Somewhat	<input type="checkbox"/> Not at all		
<b>Caregiver Priority Status (check all that apply)</b>						
<input type="checkbox"/>	Providing care to a person with Alzheimer's disease or related dementia	<input type="checkbox"/>	Grandparents or older relative caregivers who are 55+ , who are providing care for children with severe disabilities			
<b>Optional targeting categories (check all that apply)</b>						
<input type="checkbox"/>	Caregiver recently hospitalized	<input type="checkbox"/>	Care recipient requires assistance with three or more ADLs			
<input type="checkbox"/>	Care recipient recently hospitalized	<input type="checkbox"/>	Caregiver's income is at or below federal poverty level			
<input type="checkbox"/>	Caregiving is likely to continue indefinitely	<input type="checkbox"/>	Caregiver is caring for more than one person			
<input type="checkbox"/>	Care recipient is at risk for institutionalization	<input type="checkbox"/>	Other:			
<input type="checkbox"/>	Caregiver has chronic health condition or has had a recent health crisis		Notes:			

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Care Coordinator's Name

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## Appendix B: Caregiver Status Questionnaire



Form 1027  
February 2011-E

### Caregiver Status Questionnaire

Caregiver declined to answer:  Yes  No  
 Date of follow up (mm/dd/yyyy): \_\_\_\_\_  
 Attempt to contact failed:  Yes  No

**Caregiver Demographics**

DADS Staff		Date	
Caregiver Name		Telephone	
Address			
City	State	ZIP Code	County
Hispanic Origin? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer			
<b>What is your race?</b>			
<input type="checkbox"/> American Indian/Alaskan Native	<input type="checkbox"/> Black/African American	<input type="checkbox"/> White	<input type="checkbox"/> Refused to answer
<input type="checkbox"/> Asian	<input type="checkbox"/> Native Hawaiian/Other Pacific Islander	<input type="checkbox"/> None of the above	
Age: _____ <input type="checkbox"/> Refused to answer	Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Refused to answer		
<b>What is your relationship to [care recipient's name]?</b>			
<input type="checkbox"/> Child	<input type="checkbox"/> Grandparent	<input type="checkbox"/> Other – Non-relative	<input type="checkbox"/> Son/Daughter-in-law
<input type="checkbox"/> Friend	<input type="checkbox"/> Life Partner	<input type="checkbox"/> Other – Relative	<input type="checkbox"/> Spouse
<input type="checkbox"/> Grandchild	<input type="checkbox"/> Neighbor	<input type="checkbox"/> Sibling	<input type="checkbox"/> Refused to answer
Marital Status:	<input type="checkbox"/> Married	<input type="checkbox"/> Not Married	<input type="checkbox"/> Refused to answer
Lives with [care recipient's name]: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer			
Distance to care recipient's home (select one):			
<input type="checkbox"/> 0 – 10 miles	<input type="checkbox"/> 11 – 40 miles	<input type="checkbox"/> 41 – 100 miles	<input type="checkbox"/> Over 100 miles <input type="checkbox"/> Refused to answer

**Caregiver Profile**

1. Are you paid to provide care for [care recipient's name]? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer • If Yes: <i>I'd like to thank you for taking the time to respond to our survey. The information you've provided will be very useful. The focus on the remainder of the questionnaire is on unpaid caregivers.</i> Stop the interview. • If No or Refused to Answer, continue.
2. Are you the only non-paid caregiver providing care to [care recipient's name]? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer
3. How long have you been providing care for [care recipient's name]? _____ Year(s) _____ Month(s)
4. How often do you provide care to [care recipient's name]? <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less than once per month <input type="checkbox"/> Refused to answer
5. Do you have children under the age of 18? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer
6. Are you also providing care to any other individuals? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer
7. Is there anyone you can call on in an emergency to fill in for you as caregiver? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused to answer
8. Are you employed? <input type="checkbox"/> Full-time <input type="checkbox"/> Part-time <input type="checkbox"/> Not employed <input type="checkbox"/> Refused to answer If No or Refused to Answer, skip to question 10.

Caregiver Profile (continued)

9a. Have your caregiver responsibilities ever affected your employment?  Yes  No  Refused to answer

- If No or Refused to Answer, skip to question 10a.
- If Yes:

9b. Can you tell me a little bit about how this is affecting your employment? For example, has your pay been affected due to having to take off work, have you had to change your work schedule, or had to take frequent leave? Have your work performance or work relationships suffered due to caregiving demands?

Use the examples below to prompt the caregiver if, based on his/her responses, he/she is having difficulties in responding to the question.

Schedule	Pay	Leave	Relationships	Performance
<input type="checkbox"/> Changed Jobs	<input type="checkbox"/> Has taken a second job	<input type="checkbox"/> Exceeded Family Medical Leave Act (FMLA)	<input type="checkbox"/> Feeling of isolation	<input type="checkbox"/> Decrease in productivity
<input type="checkbox"/> Changed Work Schedule	<input type="checkbox"/> Has taken leave without pay (LWOP)	<input type="checkbox"/> Takes leave frequently	<input type="checkbox"/> Less co-worker interaction	<input type="checkbox"/> Decreased confidence in own ability
<input type="checkbox"/> Decreased hours or went part-time	<input type="checkbox"/> Lost wages or periods with no income	<input type="checkbox"/> Used all paid leave/no leave remaining	<input type="checkbox"/> Tension or problem with co-worker	<input type="checkbox"/> Difficulty with concentration or focus
<input type="checkbox"/> Has taken extended leave with pay	<input type="checkbox"/> Missed promotion opportunity		<input type="checkbox"/> Tension or problem with supervisor	<input type="checkbox"/> Fear of losing job
<input type="checkbox"/> Quit job	<input type="checkbox"/> Received pay cut or pay decreased			<input type="checkbox"/> Perform or manage caregiver tasks at work

10a. Do you have a chronic health condition or have you experienced a recent health crisis?

Yes  No  Refused to answer

- If Yes, ask question 10b.
- If No or Refused to Answer, go to question 11a.

10b. Has your health condition affected your ability to care for [care recipient's name]?

Yes  No  Refused to answer

11a. Do you find caring for [care recipient's name] to be stressful?  Yes  No  Refused to answer

- If Yes, ask question 11b.
- If No or Refused to Answer, stop.

11b. Would you rate your stress level as:  Low  Moderate  High  Refused to answer

Referral to the Area Agency on Aging (AAA)

If the individual meets one of the following criteria, s/he may qualify for services from AAA. If so, and if the individual indicates s/he would like assistance, make the referral according to regional procedures.

AAA Eligibility Screening Criteria: The individual may qualify for services from AAA if he or she is:

- 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 who has Alzheimer's or dementia.

*I'd like to thank you for taking the time to respond to our survey. The information you've provided will be very useful in improving current services and developing additional resources and supports for caregivers throughout the state.*

If the caregiver status form is only partially completed, please explain why: