



A PROFILE OF INFORMAL CAREGIVING IN TEXAS

Report to the
Texas Legislature

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

Submitted to the
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.¹ Identifying and meeting the needs of the estimated 3.4 million caregivers in Texas² 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 receiving care, but also helps the state avoid long-term services and supports costs, which might otherwise be shifted to Medicaid. The economic value of caregiving by informal caregivers in Texas is estimated to be \$34 billion annually, with caregivers contributing over 3.2 billion hours of care.³

Between February 2012 and March 2014, the Texas Department of Aging and Disability Services (DADS) interviewed 27,503 informal caregivers providing care to individuals seeking or receiving long-term services and supports in Texas. The data collected by DADS provides further evidence 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-fourth of males who report they are providing care for their spouse.

DADS also found caregivers who are relatives of older individuals or persons with disabilities are more likely to live with their care recipient. Those living in the same household reported higher stress levels than those who do not live with their care recipient, with 8 percent of caregivers reporting no effective way to relieve their stress. 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. Only about 3 percent of caregivers reported living 11 or more miles away from the individual for whom they provide care.

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 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. Three percent fear they could lose their jobs.

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

² AARP Public Policy Institute, *Valuing the Invaluable: 2011 Update*, 2011.

³ AARP Public Policy Institute, *Valuing the Invaluable: 2011 Update*, 2011.

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 care situations to prepare for and sustain their caregiving roles. This report reflects the progress DADS and the State of Texas have made toward achieving the goals outlined in Senate Bill (S.B.) 271 (81st Legislature, Regular Session, 2009). These include 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; and supporting the tools through which the collection and analysis of data will allow one to formulate a profile or portrait of caregivers in this state. These also include coordinating and expanding outreach and public awareness of the services and supports available to assist informal caregivers statewide in preparing for and sustaining their caregiving roles; and, through the coordination with other state programs, establishing a mechanism to collect and create an inventory of respite services available statewide and developing resources 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 (S.B.) 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, 2014.

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, 81st 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.

DADS 2012 report, *A Profile of Informal Caregiving in Texas*, continued beyond Rider 38: Delivery of Caregiver Support Services and further detailed its efforts to assist informal caregivers in long-term care situations to prepare for, and sustain, their caregiving roles. This report focuses on the analysis of collected data related to informal caregivers in Texas from February 1, 2012, through March 31, 2014,⁴ and provides updated statistics, activities, and recommendations for the future support of caregivers in Texas.

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: S.B. 271 relating to informal caregiver support services, and House Bill 802, 81st Legislature, Regular Session, 2009, relating to the creation of the lifespan respite care program. S.B. 271 incorporates the 2009 recommendations⁵ of the 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 an area agency on aging (AAA); and

⁴ 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.

⁵ Texas Legislative Budget Board, *Texas State Government Effectiveness and Efficiency*, January 2009.

- analyzing the 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 which have become known as the Caregiver Status Questionnaire (CSQ) and the Caregiver Assessment Questionnaire (CAQ). Appendix A-1 and B-1 include a copy of each.

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, if appropriate, into the final version of the CSQ.

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

Pilots of the CSQ and the CAQ were held in both rural and urban areas of Texas. A two-week pilot of the CSQ in hard-copy was performed in January 2010, in selected regional intake offices across the state (regions 2, 6, 7, 8, 9). A total of 134 caregivers participated in the 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 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.

The CSQ is 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) until September 1, 2014,⁶ 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

⁶ The CBA waiver was terminated as a result of S.B. 7, 83rd Legislature, Regular Session 2013. CBA consumers transitioned to managed care on September 1, 2014.

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 a 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 directly by the AAA, the individual is referred to staff specializing in caregiver supports 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 beyond those included in the CSQ, it helps direct the discussion between the caregiver and the AAA staff in developing 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 are referred to a AAA for caregiver supports, as 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.

Discussion

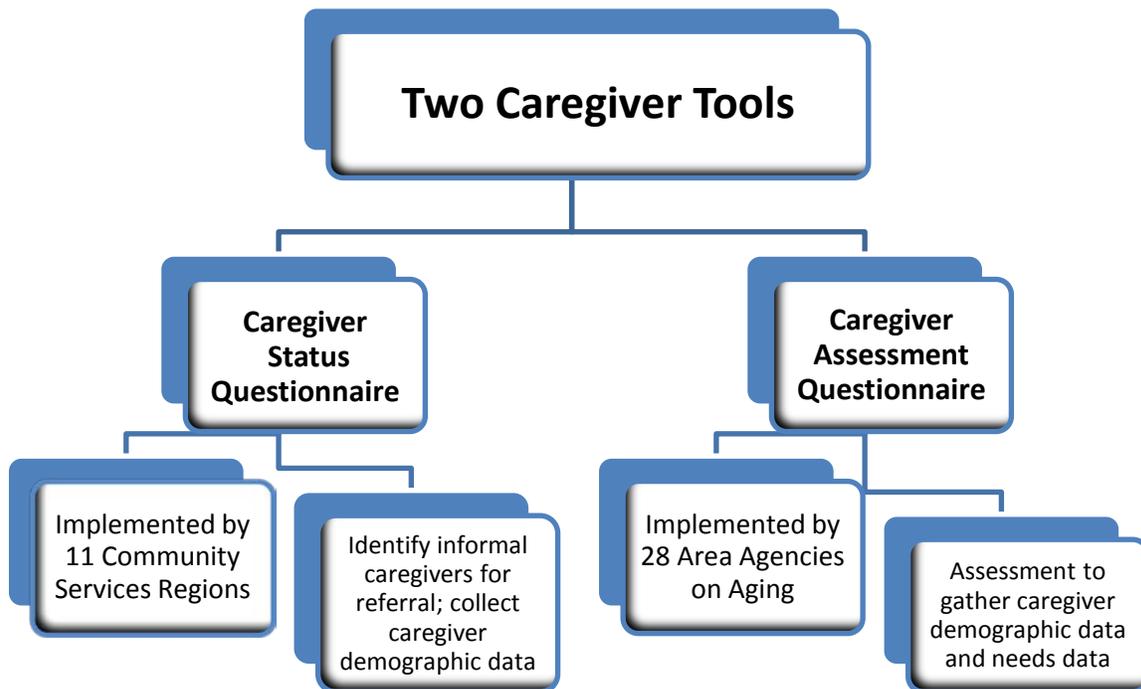
When services are requested to enable an individual to maintain their independence in the community, the caregiver often plays a crucial role. The caregiver can be a main point of contact for physicians, home health providers and others to gain information about the individual, to assist in developing a service plan to meet the individual's needs, and to help coordinate health care and support services. The caregiver is an invaluable asset, and oftentimes, 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 S.B. 271 that the data collected and analyzed as a result of this initiative 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 (until September 1, 2014), MDCP, and IHFS. The CSQ activity occurs at intake telephone contact and attempts to identify and collect information pertaining to the primary informal caregiver of the individual whose name is placed on a program interest list. Staff is not required to complete a CSQ for anyone other than the primary informal caregiver. The questions from the CSQ allow DADS to gain a demographic profile of the caregiver without assessing the needs of the caregiver. It is also used to refer people who may qualify for services provided through the OAA to AAAs.

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.



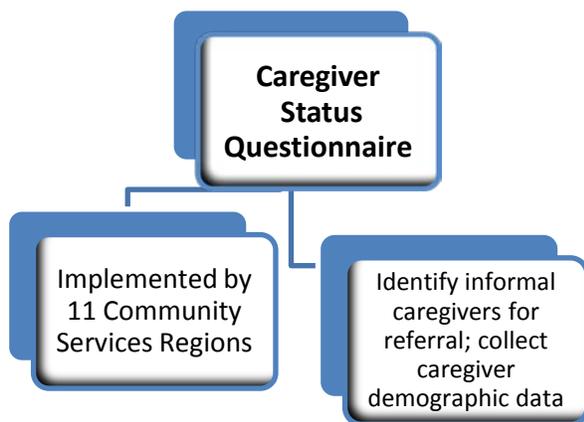
While some AAAs had previously developed and were using assessments for services under the National Family Caregiver Support Program of the OAA, no single assessment of needs for caregivers had been developed for consistent use across the state. Neither the CSQ nor the CAQ

has the capability of assigning level of risk; however, AAAs may use the CAQ, along with the Caregiver Intake and other risk assessment tools,⁷ 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, employment issues 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 S.B. 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 (until September 1, 2014), MDCP, and IHFS. 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 which may 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 refer caregivers to the AAA if it is determined the caregiver meets eligibility screening criteria. Individuals are also referred to other local resources.

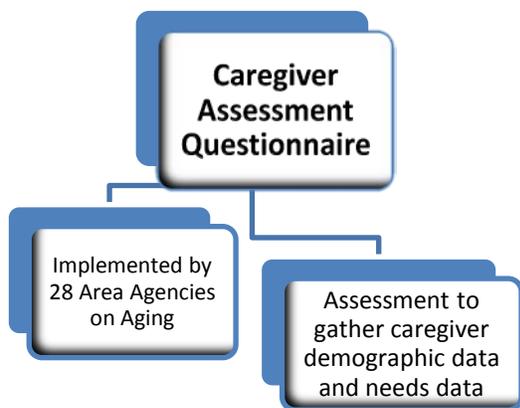
⁷ Caregiver risk assessment tools measure the risk for institutionalization for the care receiver that can result from challenges of caregiving.

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 S.B. 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.

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...”⁸ A grandparent or older individual who is a relative caregiver is defined as “a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage, or adoption who is 55 years of age or older and lives with the child; is the primary caregiver; and has a legal relationship to the child, or is raising the child informally.”⁹

Effective in 2010, and as a result of S.B. 271, caregiver needs are consistently assessed by each of the 28 AAAs in Texas using the CAQ. Developed as an assessment tool for caregivers seeking help through AAAs, and who meet the eligibility criteria as defined by the OAA, it assists AAA staff in identifying needs and appropriate services for caregivers accessing services. When appropriate, the AAA develops an individual plan of care based on needs identified through the assessment.

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 greatly assisted in care planning, but more importantly, it 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.”

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 the AAA for service planning purposes. The caregiver seeking service through the AAA may choose to not identify 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.

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.

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

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

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 the State Unit on Aging Programs Uniform Reporting System (SPURS) using a specialized data entry format.

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 IHFS. 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 Health and Human Services Region



Of the 20,279 caregivers who responded to the CSQ between February 2012 and March 2014, 233 of the 254 Texas counties were represented. The following counties experienced the highest number of caregiver calls:

- 2,223 callers – Harris County;
- 1,703 callers – Dallas County;
- 1,230 callers – Tarrant County; and
- 474 callers – Lubbock County.

The U.S. Office of Management and Budget¹⁰ 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.

¹⁰ 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/>.

Of those caregivers who spoke with DADS, 11,423 lived in 79 urban counties while 3,280 lived in 154 rural counties.

In regards to health and human services (HHS) regions, caregivers resided in all 11 HHS regions. Regions 3, 4, and 6 accounted for 63 percent of all calls. Regions with over 1,000 callers each (1, 3, 4, 6, and 7) accounted for 83 percent of callers, while regions 2, 5, 8, 9, 10, and 11 accounted for 17 percent of callers.

The 7,224 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 Harris, Dallas, Tarrant, Bexar, Cameron, and El Paso. These counties represented the highest number of caregiver assessments completed. The number of caregivers assessed by county included:

- 618 residing in Harris County (Harris County AAA);
- 514 residing in Dallas County (Dallas County AAA);
- 437 residing in Tarrant County (Tarrant County AAA);
- 300 residing in Bexar County (Bexar County AAA);
- 274 residing in Cameron County (Lower Rio Grande AAA); and
- 249 residing in El Paso County (Rio Grande AAA).

The CAQ is required only when the caregiver receives support coordination. Caregivers are assessed as identified by the local AAA, rather than being assessed 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 (67 percent) were not aware of caregiver support services prior to contacting the AAA for assistance.

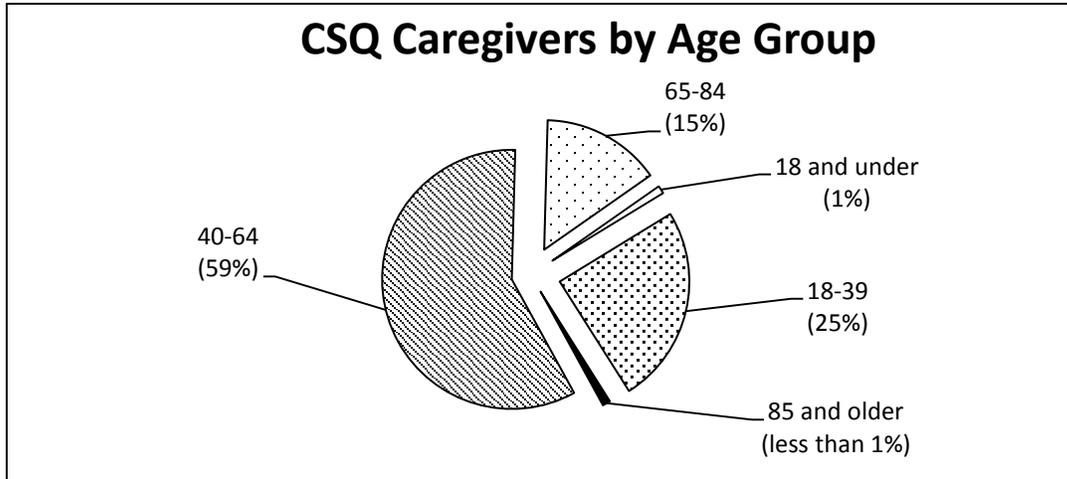
Demographic Characteristics of Caregivers

Whites were the predominant group of caregivers (42 percent) among CSQ respondents; in 2012, Hispanics were predominant. The next largest group consisted of Blacks/African Americans (30 percent) followed by Hispanics (26 percent). American Indian/Alaskan Native and Native Hawaiian/Other Pacific Islander made up one percent of respondents while Asians made up less than 1 percent of the respondents.

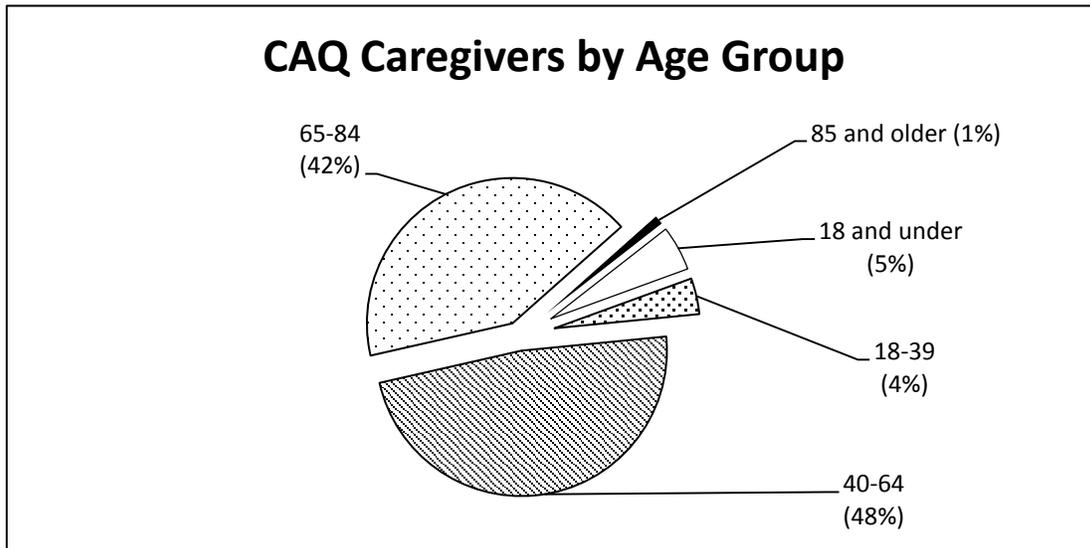
The majority of caregivers assessed by AAAs using the CAQ were White (45 percent), with the next largest group reporting to be of Hispanic origin (32 percent), followed by Black/African American (20 percent). Asians represented 1 percent of caregivers assessed, with American Indian/Alaskan Native and Native Hawaiian/Other Pacific Islander each comprising less than 1 percent. As the following chart¹¹ shows, the majority of caregivers were between the ages of 40 and 64, making up 59 percent of CSQ respondents. Caregivers between the ages of 18 and 39

¹¹ Age ranges for this report differ slightly from the 2012 report to follow the standard across the Health and Human Services Commission for reporting data.

made up the next largest group at 25 percent, followed by caregivers between 65 and 84 years of age (15 percent). One percent of caregivers were 18 and under and less than 1 percent were 85 and older.



As was the case with the CSQ, the majority of caregivers assessed through the CAQ were between the ages of 40 and 64, making up 48 percent. Caregivers between the ages of 65 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 was 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. Thirty-seven 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 27 percent, and for those who are age 65-84, 20 percent reported being in poverty. Eighteen percent of the caregivers age 85 and older reported living in poverty. Women were slightly more likely to report living in poverty than men, 26 percent versus 22 percent. Although the percentage of women and men in poverty is lower than the 2012 results of 34 percent versus 29 percent respectively, the ratio between women living in poverty to the number of men living in poverty remains similar in 2014 to 2012.

Similar to the 2012 results, seventy-two percent of caregivers assessed through the CAQ 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, 76 percent were female; for the 40-64 age group, 78 percent were female; for the 65-84 age group, 66 percent were female; and for those 85 years and older, 51 percent were female.

Caregivers and Relationship to Care Recipient

Relatives of care recipients primarily served as the informal caregiver. The majority of caregivers were children or spouses of the care recipients. The data reflects 25 percent of men were more likely to be the spouse of their care recipient, while 48 percent of women were more likely to be caring for a parent. However, differences existed between questions for percentages of children and spouses providing care. Spouses represented 33 percent of caregivers responding to the CAQ and 16 percent of CSQ respondents; in 2012 spouses represented 49 percent of CSQ respondents, which may indicate the state is reaching broader cohorts of caregivers. Children of the care recipient represented 37 percent of the CAQ data and 47 percent of the CSQ data.

On the CAQ, other relatives, including son/daughter-in-law, grandchild, grandparent, other relative, and sibling accounted for 22 percent of all caregivers. Friends, neighbors, and other non-relatives accounted for fewer than 4 percent of caregivers. On the CSQ, 11 percent were other relatives to the care recipient, while grandchildren, grandparents, life partners, or siblings made up 13 percent of caregivers who responded. Non-family members, such as friends, neighbors, and other non-relatives, made up fewer than 4 percent of caregivers according to the CAQ. More non-family members (12 percent) served as caregivers as reported in the CSQ.

Caregivers' Family Composition

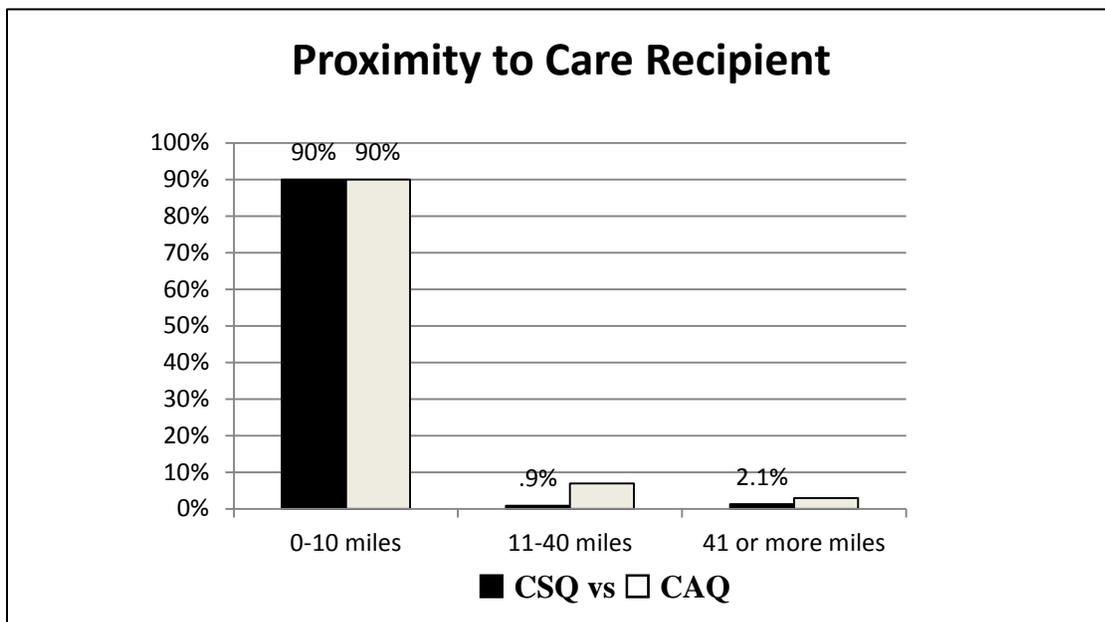
Most respondents to the CAQ reported being married, at 66 percent, and 81 percent indicated they did not have children under the age of 18. This is similar to the composition of caregivers responding to the CSQ, with 48 percent married and 75 percent reporting no children under the age of 18.

The percent by race/ethnicity who reported having children under the age of 18 was relatively dissimilar among this reporting group. Of the CAQ respondents, 22 percent of Asians, 20 percent of Hispanics, 16 percent of Black/African Americans, and 11 percent of Whites reporting this information had children under the age of 18. The CSQ data indicated Hispanics (30 percent) and

other racial/ethnic groups (29 percent) were more likely to report having children under the age of 18. Twenty-eight percent of Blacks/African Americans, 22 percent of Whites, and 19 percent of Asians 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 70 percent (CSQ) and 71 percent (CAQ). On the CSQ, a higher proportion of urban caregivers, 71 percent, as compared to rural caregivers, 68 percent, reported living with the care recipient. The majority, 90 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 (94 percent), regardless of race/ethnicity, were not paid to provide care to the recipient, according to CSQ data. In addition, many caregivers, 77 percent, indicated they were the only non-paid caregiver for the care recipient.

CAQ data reports 96 percent of the caregivers as being non-paid caregivers.¹² Of the total caregivers assessed, 60 percent reported being the only non-paid person providing care to the care recipient, compared to 77 percent of CSQ respondents.

¹² The Older Americans Act does not allow funding for services to paid caregivers.

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, 95 percent, provided care at least once per week, regardless of race or ethnicity. Slightly less than 2 percent assisted the care recipient monthly. On the CSQ, 94 percent of caregivers reported providing care every day. About 5 percent provided care weekly, and less than 1 percent provided care monthly or less. Most caregivers had someone to call on in an emergency, as reported on the CAQ (78 percent) and CSQ (64 percent). As a result, almost one-fourth, or 18 percent, of CAQ respondents reported having no other person to call to fill in as caregiver as needed, such as in an emergency. Thirty-six percent of CSQ respondents also did not have someone to call on to fill in.

In addition, the CSQ focused on length of time a caregiver had provided care. Twenty-one 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 29 percent. Some caregivers had been providing care between 2 and 5 years (29 percent) and some had been providing care between 5 and 10 years (11 percent). Another 7 percent had been providing care for 10 years or more. Two percent had only been providing care for less than one month. Caregivers are also performing many more complex medical or skilled nursing tasks. A recent AARP Public Policy Institute study, *HOME ALONE: Family Caregivers Providing Complex Chronic Care* notes, “Almost half (46 percent) of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions. These tasks include managing multiple medications, helping with assistive devices for mobility, preparing food for special diets, providing wound care, using monitors, managing incontinence, and operating specialized medical equipment.”¹³

Of employed caregivers:

- 1 percent reported they had quit work
- 8 percent reported they had changed work schedules
- Less than .5 percent reported taking a second job
- 18 percent reported they take leave frequently
- 1 percent reported they had exceeded Family Medical Leave Act limits
- About 3 percent reported they feared losing their job

Effects of Caregiving on Employment

Similarly, over one-half of the caregivers indicated they were not employed on both the CSQ (69 percent) and CAQ (61 percent). Approximately 20 percent of CSQ respondents and 27 percent of CAQ respondents were employed full-time. Those employed part-time accounted for 11 percent of CSQ respondents and 9 percent of CAQ respondents.

Those caregivers who were employed full-time or part-time were asked a variety of questions about the effects

¹³ Susan C. Reinhard, RN, PhD, FAAN, Carol Levine, MA, Sarah Samis, MPA, *Home Alone: Family Caregivers Providing Complex Chronic Care* (United Hospital Fund, AARP Public Policy Institute, October, 2012)

of caregiving on employment. According to the CSQ findings, caregivers reported few negative impacts on their employment as a result of providing care to another person.

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.”¹⁴

Among CAQ respondents, 28 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, 9 percent of Asians and other racial/ethnic groups, 6 percent of Whites, 5 percent of Hispanics, and 4 percent of Blacks/African Americans reported to have lost wages or to have had periods with no income due to caregiving responsibilities. Hispanics (25 percent), Whites (20 percent), and Asians (13 percent) were more likely to take leave frequently because of caregiving responsibilities than Blacks/African Americans (12 percent) or people in other racial/ethnic groups (9 percent) were.

By race or ethnicity from the CAQ findings, Native Hawaiian/Other Pacific Islander were more likely to report being employed full-time, at 66 percent. Thirty-one percent of Black/African Americans, 28 percent of Hispanics, and 23 percent of Whites worked full-time. Sixty-one percent of caregivers reported they currently do not work. Sixty-seven percent of Whites, 60 percent of Hispanics, and 54 percent of Blacks/African Americans 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 6 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.”¹⁵ DADS CSQ and CAQ data on employment may, in part, reflect these caregivers who chose to leave the workforce to provide care.

¹⁴ 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)

¹⁵ 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>

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.¹⁶

Impact of Caregivers' Health Issues on Caregiving

Care for others impacts the health of caregivers 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 42 percent of caregivers responding to the CAQ. More than half (52 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, 30 percent stated their health has affected their ability to provide care for the care recipient.

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."¹⁷

Stress Level of Caregivers

The majority of caregivers responding to both the CSQ and CAQ reported caregiving as stressful. Fifty-one percent of caregivers reporting on the CSQ found caregiving to be stressful. Of those who found caregiving to be stressful, 48 percent rated their stress level as moderate. Thirty-one percent said their stress level was high, and 22 percent of respondents indicated their stress level was low.

CAQ data tells us 75 percent of caregivers find caregiving to be stressful, with 28 percent reporting their stress level as high. Somewhat lower than 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 84 percent reported feeling confident about providing care. Sixty-three percent of caregivers agreed or strongly agreed providing care while meeting other family and work responsibilities was stressful, and 84 percent of caregivers felt they had an obligation to provide care to the care recipient. In addition, 31 percent of caregivers reported they could do a better job of providing care than someone else could.

¹⁶ *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business* (2006)

¹⁷ Schulz, R. & Beach, S. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study, *JAMA*, 282: 2215-2219.

Thirty-nine percent reported agreeing or strongly agreeing their finances are strained due to providing care. Overall, Whites most frequently reported their finances were strained because of caregiving. Financial strain was reported by 44 percent of Whites, 41 percent of Asians, 37 percent of Hispanics, and 35 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 59 percent reported engaging in activities which effectively relieve stress, 26 percent reported activities “somewhat” relieve stress and a full 8 percent reported finding no effective ways to relieve stress. Thirteen percent indicated they would like information, education, and/or training about caring for oneself 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, 32 percent reported high stress levels, 47 percent reported moderate, and 21 percent reported low levels of stress. Among those who did not live with the care recipient, 25 percent reported high levels of stress, while 53 percent reported moderate, and 23 percent reported low levels of stress. Similar to the CSQ finding, 30 percent of caregivers responding to the CAQ who reported living with the care recipient rated their stress level as high, versus 23 percent of those who did not live with the care recipient.

Stress levels increase the closer a caregiver lives to the care receiver as CAQ data revealed. High stress levels were reported by 29 percent of caregivers living within 10 miles of the recipient, 24 percent of those living 11 to 40 miles, and 21 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, 35 percent reported high stress levels, and 47 percent reported moderate stress levels. Of those employed part-time, 26 percent reported high stress levels, and 48 percent reported moderate stress levels. Of those caregivers who were not employed, 29 percent reported high stress levels and 48 percent reported moderate stress levels.

Twenty-six percent of caregivers reported working full-time on the CAQ. Of those, 33 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, 32 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 were 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, 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, 36 percent reported higher stress levels, as compared to 29 percent of those who provide care to only one care recipient.

Of all caregivers surveyed through the CAQ, 70 percent reported they were not caring for more than one person, significantly lower than those responding to the CSQ. Of those who are providing care for more than one person, 32 percent reported high stress. Twenty-seven percent reported high stress when caring for only one person. Data revealed a significant variance in stress when providing care to either one or more than one person.

Caregiver Assessment Questionnaire Support Tasks Performed by Caregivers

A high percentage of caregivers provide significant assistance when taking care of another person. Eighty-five percent reported helping the care recipient with homemaker chores and 72 percent of caregivers reported helping the care recipient with personal care tasks. Ninety percent reported helping the care recipient with health care (doctor visits, medication monitoring), 85 percent reported helping the care recipient with transportation, and 73 percent reported helping the care recipient with managing finances. Eighty-five percent reported helping the care recipient by providing emotional support, and 80 percent reported the need to provide supervision to the care recipient.

Support Tasks Provided

Percent of Caregivers Providing Support Tasks	Support Task
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 (e.g., bathing, grooming, etc.)

Caregivers assessed reported a high level of responsibility in taking care of the recipient. Eighty-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. Over a third, 35 percent, reported the care recipient has Alzheimer's disease or related dementia. With 39 percent of care recipients having been hospitalized recently, and 9 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.

Caregiver Assessment Questionnaire Caregiver Knowledge and Acceptance of Support Services

Most caregivers (67 percent) were not aware of support services prior to contacting the AAA, and 57 percent had not received caregiver support services in the past. Eleven percent of caregivers reported reluctance to accepting outside help. This reluctance to accept outside help was based on a lack of trust of service providers in the home as expressed by 6 percent of caregivers, or the feeling no one else can provide care as well as they do (12 percent). Almost one-third, or 29 percent, had other concerns about receiving caregiver support, regardless of the fact 85 percent reported their caregiving is likely to continue indefinitely.

Caregiver Assessment Questionnaire Caregiver Knowledge of Care Recipient’s Condition

More than one-half of caregivers, 64 percent of those responding to this question, indicated they felt “very” knowledgeable about the care recipient’s disease or condition. Thirty-two percent reported feeling “somewhat” and four 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
25	In-home support services
13	Home safety and/or home modifications or equipment
11	How to provide care to an aging individual
11	Care recipient’s disease or condition
10	Support groups
9	How to get other family members to help
8	Long-term care options (e.g., insurance and/or other benefits)
6	Short-term respite care in a facility
5	Legal and financial issues, powers of attorney, living will
4	Individual counseling options
4	Hands-on skills training for personal care tasks (e.g., bathing, grooming, etc.)
4	On-line information and supports
3	How to choose a long-term care facility

Approximately two-thirds (64 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 percent of caregivers reported engaging in activities which effectively relieve stress; however, 26 percent reported their activities were “somewhat” effective at relieving stress, and 8 percent reported finding no effective ways to relieve their stress.

Conclusions

- Of all caregivers assessed using the CSQ and CAQ, majority were age 40 to 64.
- Compared to the 2012 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 relation 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 reside. A slight majority of caregivers assessed using the CSQ were not married.
- A majority of caregivers lives with the care recipient and is 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.
- Eight percent of caregivers found no effective way to relieve stress.
- Caregiver knowledge about a care recipient's condition appeared to reduce stress.
- Caregiving responsibilities negatively affected the work of employed caregivers. An average of sixty-four 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 will continue indefinitely, with almost one-half believing the care recipient is at risk of institutionalization. Only 3 percent requested information about choosing a long term care facility.
- 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, home safety and home modification, and caring for an aging individual. In 2012, support groups were among the top three, rather than 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 S.B. 271 workgroup identified what changes will be made to DADS current intake processes to ensure sustained, ongoing data collection and 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 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 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, a result of S.B. 271 and H.B. 802, 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, and awareness and use of respite and other caregiver support services. Caregivers across the state completed the survey online, 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 revealed 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, and 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.”¹⁸ 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 remainder had been providing care for less than one year.
- 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 respite care from medical providers (24 percent), friends or family (23 percent), and ADRCs (15 percent).

These survey outcomes reveal that even though the majority of caregivers (63 percent) knew what respite care was, less than half (40 percent) had used respite services and 67 percent did not know how to find a licensed, reputable provider. DADS Access and Intake staff have taken measures to address these outcomes by launching an outreach effort to increase awareness of the Take Time Texas website. Staff is also working to expand the inventory of respite services, allowing more caregivers to find services in their community.

Currently DADS is conducting an extensive project to enhance the Take Time Texas website, which is the online central hub for respite resources in Texas. DADS staff, including several members of the internal web and marketing team, have developed a communications plan outlining the goals, objectives, and strategies of the website and have received feedback from the Respite Coalition on these activities. The goal of this project is to increase user interaction, awareness of the Take Time Texas website, average time spent on the website, the information provided on the respite locator database, and to make the site more user friendly overall.

¹⁸ 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*, 92(2) 305-1311.

The DADS media team utilized Google analytics, website user surveys, market analysis and research on other similar websites to guide the redesign process. The inventory of respite services is also being redesigned to increase the accuracy and availability of provider information and increase ease of navigation.

DADS Access and Intake division will regularly coordinate 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.

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 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. 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.¹⁹
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 caregivers who must pick up the extra workload, which requires training and support they do not have, and which adds to their caregiving burden.”²⁰
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, training, and support services, such as home modifications and short-term respite.

¹⁹ 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)

²⁰ Donelan, K., et al. (2002) Challenged To Care: Informal Caregivers in a Changing Health System. *Health Affairs*, July/August 2002, 222-231.

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. 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.
8. 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.
9. 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.
10. Disseminate findings of data analyses to stakeholders to support the development of effective local plans to serve caregivers.



Appendix A-1

Caregiver Assessment

Date: _____

<p>1. Caregiver's first name:</p> <p>2. Caregiver's last name:</p> <p>3. Care recipient's first name:</p> <p>4. Care recipient's last name:</p>	<p>5. Caregiver's relationship to care recipient:</p> <table style="width:100%;"> <tr> <td><input type="checkbox"/> Child</td> <td><input type="checkbox"/> Other Relative</td> </tr> <tr> <td><input type="checkbox"/> Friend</td> <td><input type="checkbox"/> Other Non-Relative</td> </tr> <tr> <td><input type="checkbox"/> Grandchild</td> <td><input type="checkbox"/> Sibling</td> </tr> <tr> <td><input type="checkbox"/> Grandparent</td> <td><input type="checkbox"/> Son/Daughter-in-Law</td> </tr> <tr> <td><input type="checkbox"/> Life Partner</td> <td><input type="checkbox"/> Spouse</td> </tr> <tr> <td><input type="checkbox"/> Neighbor</td> <td><input type="checkbox"/> Refused to Answer</td> </tr> </table>	<input type="checkbox"/> Child	<input type="checkbox"/> Other Relative	<input type="checkbox"/> Friend	<input type="checkbox"/> Other Non-Relative	<input type="checkbox"/> Grandchild	<input type="checkbox"/> Sibling	<input type="checkbox"/> Grandparent	<input type="checkbox"/> Son/Daughter-in-Law	<input type="checkbox"/> Life Partner	<input type="checkbox"/> Spouse	<input type="checkbox"/> Neighbor	<input type="checkbox"/> Refused to Answer
<input type="checkbox"/> Child	<input type="checkbox"/> Other Relative												
<input type="checkbox"/> Friend	<input type="checkbox"/> Other Non-Relative												
<input type="checkbox"/> Grandchild	<input type="checkbox"/> Sibling												
<input type="checkbox"/> Grandparent	<input type="checkbox"/> Son/Daughter-in-Law												
<input type="checkbox"/> Life Partner	<input type="checkbox"/> Spouse												
<input type="checkbox"/> Neighbor	<input type="checkbox"/> Refused to Answer												

<p>6. Caregiver Demographics and Living Arrangement</p> <table style="width:100%;"> <tr> <td>a. Marital Status:</td> <td><input type="checkbox"/> Married</td> <td><input type="checkbox"/> Not Married</td> <td><input type="checkbox"/> Refused</td> </tr> <tr> <td>b. Hispanic Origin:</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> <td><input type="checkbox"/> Refused</td> </tr> <tr> <td>c. Race:</td> <td><input type="checkbox"/> Asian</td> <td><input type="checkbox"/> Black</td> <td><input type="checkbox"/> Native Hawaiian Other Pacific</td> </tr> <tr> <td>d. Lives with care recipient:</td> <td><input type="checkbox"/> White</td> <td><input type="checkbox"/> Refused</td> <td><input type="checkbox"/> Refused</td> </tr> <tr> <td></td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> <td></td> </tr> </table>	a. Marital Status:	<input type="checkbox"/> Married	<input type="checkbox"/> Not Married	<input type="checkbox"/> Refused	b. Hispanic Origin:	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Refused	c. Race:	<input type="checkbox"/> Asian	<input type="checkbox"/> Black	<input type="checkbox"/> Native Hawaiian Other Pacific	d. Lives with care recipient:	<input type="checkbox"/> White	<input type="checkbox"/> Refused	<input type="checkbox"/> Refused		<input type="checkbox"/> Yes	<input type="checkbox"/> No		<p>7. Assessment Time Start:</p> <p>8. Assessment Time End:</p> <p>9. Total Time:</p>
a. Marital Status:	<input type="checkbox"/> Married	<input type="checkbox"/> Not Married	<input type="checkbox"/> Refused																		
b. Hispanic Origin:	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Refused																		
c. Race:	<input type="checkbox"/> Asian	<input type="checkbox"/> Black	<input type="checkbox"/> Native Hawaiian Other Pacific																		
d. Lives with care recipient:	<input type="checkbox"/> White	<input type="checkbox"/> Refused	<input type="checkbox"/> Refused																		
	<input type="checkbox"/> Yes	<input type="checkbox"/> No																			

Caregiver Needs	
10. Were you aware of the caregiver support resources prior to making this contact?	<input type="checkbox"/> Yes <input type="checkbox"/> No
11. If YES , have you received caregiver support services in the past?	<input type="checkbox"/> Yes <input type="checkbox"/> No
12. If NO , what prompted you to seek help now?	
13. Do you have concerns about receiving the caregiver support? (Check all that apply)	
<input type="checkbox"/> Care recipient reluctant to accept outside help	<input type="checkbox"/> No one else can provide care as well as I do
<input type="checkbox"/> Do not trust service providers in the home	<input type="checkbox"/> Other
14. If "Other" was indicated above, please describe:	

Caregiver Profile		
15. Are you paid to provide care for [care recipient's name]?	<input type="checkbox"/> Yes <input type="checkbox"/> No	(If Yes , stop here)
16. Are you the only non-paid person providing care to [care recipient's name]?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Refused to Answer
17. How long have you provided care for [care recipient's name]?	<input type="checkbox"/> year(s) <input type="checkbox"/> month(s)	
18. How often do you provide care to [care recipient's name]?	<input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less than Once per Month <input type="checkbox"/> Refused to Answer	
19. Do you have children under the age of 18?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Refused to Answer
20. Are you also providing care to any other individuals?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Refused to Answer
21. Is there anyone you can call on in an emergency to fill in for you as a caregiver?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Refused to Answer
22. Distance to care recipient's home: (Select one)	<input type="checkbox"/> 0 – 10 miles <input type="checkbox"/> 11 – 40 miles	<input type="checkbox"/> Refused to Answer
	<input type="checkbox"/> 41 – 100 miles <input type="checkbox"/> Over 100 miles	
23. Do you have a chronic health condition or have you experienced a recent health crisis? (If No , go to question 25)	Caregiver's health condition/crisis:	<input type="checkbox"/> Yes <input type="checkbox"/> No
24. Has this health condition affected your ability to care for [care recipient's name]?		<input type="checkbox"/> Yes <input type="checkbox"/> No

Caregiver's Name:		Date:				
Care Recipient's Name:						
Caregiver Stress Interview						
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	
Check the response that best describes how you feel:	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Refused to Answer
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		
Caregiver Priority Status (check all that apply)						
<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			
Optional targeting categories (check all that apply)						
<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:			

Care Coordinator's Name

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				
What is your race?				
<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		
What is your relationship to [care recipient's name]?				
<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	
<ul style="list-style-type: none"> • If Yes: <p style="margin-left: 20px;"><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></p> <p style="margin-left: 20px;">Stop the interview.</p> • 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) <input type="text"/> Month(s) <input type="text"/>
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: