



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

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**As Required by  
Section 161.079(g), Human  
Resources Code**

**Texas Health and Human Services  
Commission**

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**TEXAS**  
Health and Human  
Services

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## Executive Summary

[Section 161.079\(g\), Human Resources Code](#), requires the Texas Health and Human Services Commission (HHSC) to submit a report on strategies implemented to collect and analyze data related to informal caregiver support services which are to be used to identify and understand the needs of informal caregivers and strengthen the delivery of informal caregiver support services. HHSC must submit the report to the Governor and the Legislative Budget Board no later than December 1 of each even-numbered year.

Across Texas, 11 HHSC regions, 28 area agencies on aging (AAAs), and 28 aging and disability resource centers (ADRCs) work collaboratively to expand outreach and public awareness of services and supports available to help people prepare for and sustain their role as informal caregivers.

In 2012, the Take Time Texas initiative commenced as an effort to increase the availability of respite services for family members who care for a person of any age with any chronic health condition or disability. HHSC, in coordination with state programs and local providers, launched [TakeTimeTexas.org](http://TakeTimeTexas.org). The website provides an online inventory of respite services that enables caregivers to locate services and supports available within their respective communities throughout Texas.

Between April 1, 2018, to March 31, 2020, HHSC interviewed 10,285 informal caregivers from HHSC community services and AAA programs. The data collected by HHSC provides further evidence that:

- Relatives (most often a spouse or adult child) are the primary informal caregivers in Texas;
- Caregivers living with the care recipients reported higher stress levels than those who do not live with the care recipients; and
- Some caregivers reported no effective way to relieve their stress.

In addition, a small percentage of informal caregivers who reported full or part-time employment reported having to quit a job due to caregiving and stress levels.

Based on the data and analysis of caregiver demographics and need, HHSC will continue to improve programs supporting caregivers through public awareness of needs and services, support services, educational opportunities, consumer-directed models of service delivery, evidenced-based interventions, data collection and analysis, and new services to address evolving caregiver needs.

# 1. Introduction

Informal caregivers are relatives and friends who provide unpaid care to older people and people with disabilities. In Texas, an estimated 3.4 million caregivers care for older adults and people with disabilities, enabling the person receiving care to age in place and delay the need for institutional placement, providing for nearly 3 billion care hours each year.<sup>1</sup>

Senate Bill 271, 81st Legislature, Regular Session, 2009, added Section 161.079 to the Human Resources Code, requiring the legacy Department of Aging and Disability Services, now HHSC, to:

- Coordinate with AAAs to raise public awareness of support services available to informal caregivers;
- Implement a caregiver status assessment into the existing Medicaid process to identify and collect information pertaining to primary informal caregivers;
- Establish a protocol and standardized assessment tool for the AAAs to use to evaluate the needs of caregivers of people who are eligible to receive Older Americans Act services; and
- Use tools for the collection and analysis of data to allow for the formulation of an informal caregiver profile in Texas.

Using the data analyzed, HHSC must:

- Evaluate the needs of assessed informal caregivers;
- Measure the effectiveness of certain informal caregiver support interventions;
- Improve existing programs;
- Develop new services as necessary to sustain informal caregivers; and
- Determine the effect of informal caregiving on employment and employers.

The 2020 report, *A Profile of Informal Caregiving in Texas*, includes data collected from April 1, 2018, to March 31, 2020.

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<sup>1</sup> "Valuing the Invaluable 2019 Update: Charting a Path Forward," November 2019, <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>

## 2. Background

Informal caregivers are considered the backbone of the long-term care system. They often help with daily activities, such as bathing and bathroom functions, feeding, grooming, managing medication, and may also help manage appointments with doctors and provide or arrange transportation.

Many caregivers are unprepared to assume the role of caregiver when the time comes. Helping them prepare for and sustain their roles as caregivers has a positive impact on them and the person receiving care. Additionally, this assistance helps the state avoid long-term services and supports costs.

To evaluate the needs of informal caregivers, HHSC and the AAAs use the Caregiver Assessment Questionnaire (CAQ) and the Caregiver Status Questionnaire (CSQ). These questionnaires are used to determine placement of care recipients on program interest lists or to develop a care plan for services.

Since the last reporting period, caregiver support services show an overall increase in caregivers served. The 20.7 percent increase in CAQ interviews is likely due to a growing aging population accessing home and community-based services, increased utilization of community partnerships for outreach, and increased utilization of in-home caregiver respite across the state (Table 1). The number of CSQ interviews, which are conducted when people call HHSC seeking services, declined by 8.2 percent in the same time period. This may be attributed to the voluntary nature of the CSQ interview.

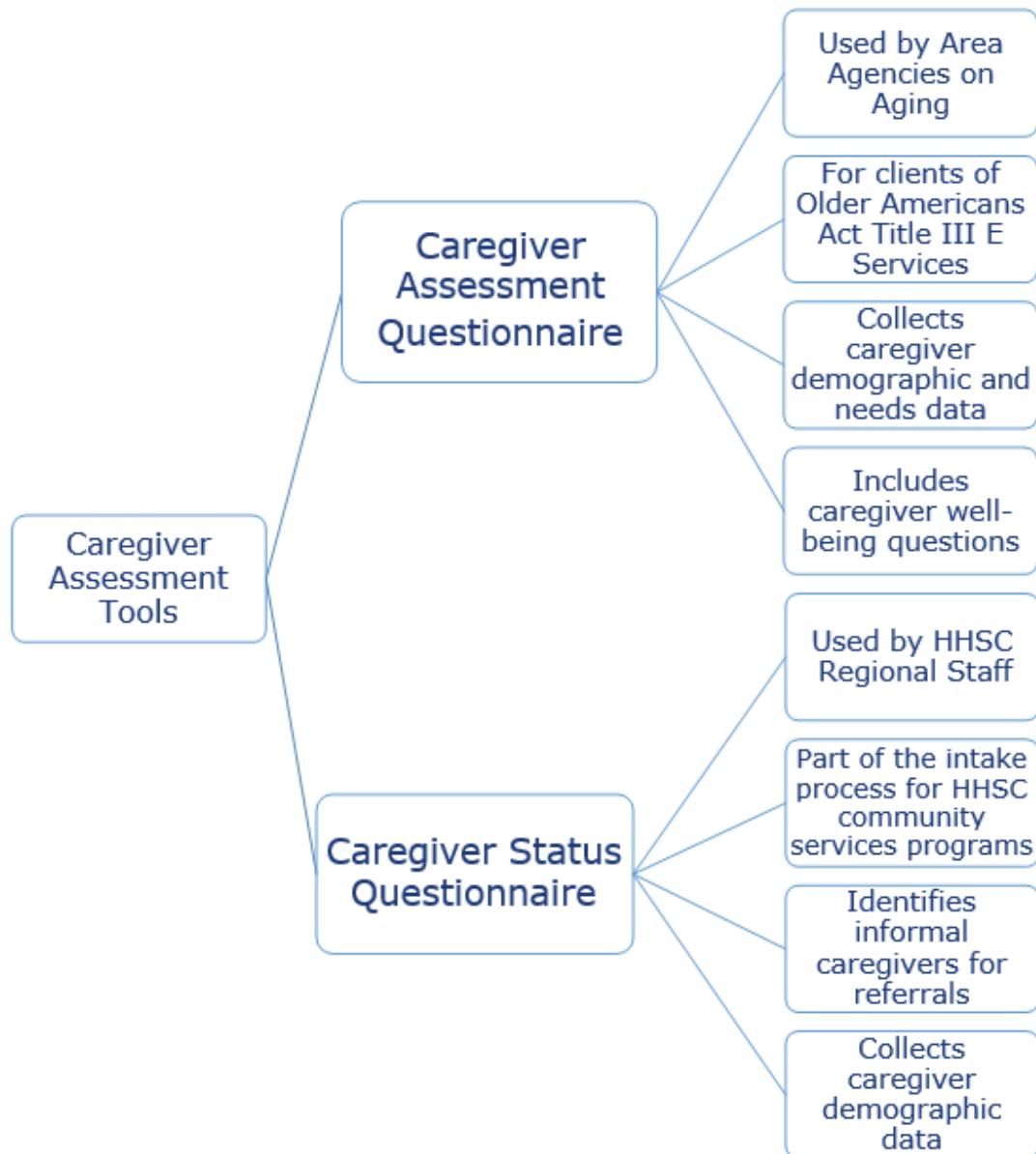
**Table 1. CAQ and CSQ Interviews**

| Assessment Period     | CAQ          | CSQ          | Total Number of Interviews |
|-----------------------|--------------|--------------|----------------------------|
| 4/1/2018–3/31/2020    | 7,619        | 2,666        | 10,285                     |
| 4/1/2016–3/31/2018    | 6,311        | 2,905        | 9,216                      |
| <b>Percent Change</b> | <b>20.7%</b> | <b>-8.2%</b> | <b>11.6%</b>               |

### 3. Caregiver Assessment Tools

HHSC, along with the AAAs, uses the CAQ and the CSQ to evaluate the needs of informal caregivers. These questionnaires are used to determine placement of care recipients on program interest lists or to develop a care plan for services (Figure 1).

**Figure 1. Caregiver Assessment Tools**



Local AAAs complete the CAQ to identify a caregiver's needs and services for all caregivers receiving caregiver support services funded through Title III-E of the Older Americans Act. HHSC Community Care Services Eligibility regional intake staff use the CSQ to identify a person who is a caregiver and provide a profile of the caregiver for referral to HHSC programs (e.g., Take Time Texas, ADRC resources, and AAA).

## Caregiver Assessment Questionnaire

Section 161.079(e), Human Resources Code, requires a standardized caregiver assessment and protocol for caregivers accessing services through a AAA. Since 2010, the 28 AAAs in Texas have used the CAQ to assess caregiver needs.

The CAQ is completed for all caregivers receiving Caregiver Support Coordination funded through Title III-E of the Older Americans Act, also known as the National Family Caregiver Support Program. AAA staff use the CAQ information 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, taking into consideration the preferences of the caregiver and care recipient.

The CAQ identifies areas in which a caregiver might need education or training to enhance their knowledge and skills and understand how to achieve a family-centered approach to caregiving. The CAQ also includes questions to assess the caregiver's physical and mental health status. The relational categories included in Table 3 are the categories included in both the CAQ and CSQ.

CAQ data also helps identify caregivers meeting the Act's priority populations,<sup>2</sup> as well as targeted populations for outreach and public awareness efforts. Caregivers seeking services through the AAA can choose not to identify the source of their referral; therefore, some duplication of data can result for people who completed the CSQ and were subsequently referred to the AAA by the regional intake office.

A person, or another person contacting the AAA on behalf of a person, may request caregiver support services by telephone, mail, email, fax, or in person. 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. When a caregiver receives care coordination, the AAA staff

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<sup>2</sup> Older Americans Act, as amended in 2020, 42 U.S.C. §3026

completes the CAQ and enters the information into the State Unit on Aging Programs Uniform Reporting System (SPURS) using a specialized data entry format.

## Caregiver Status Questionnaire

The CSQ identifies and collects information pertaining to primary informal caregivers in response to Section 161.079(d), Human Resources Code, which requires HHSC to implement a caregiver status assessment into the existing Medicaid process. The purpose of the voluntary questionnaire is to develop a profile of informal caregivers and to make appropriate referrals from HHSC staff to the AAA for support services.

The CSQ eligibility screening criteria for AAA services are:

- 60 years of age or older and caring for a person of any age; or
- 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; and/or
  - ▶ Is caring for a person of any age with Alzheimer’s disease or dementia.

A person may request 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 person. Depending on the program, people in need of services might be eligible at any age; therefore, caregivers comprise a wide range of age groups.

HHSC staff provides general information about HHSC programs, determines the type of service requested, refers the person to the appropriate HHSC program, and makes referrals to other state or community agencies when applicable. To begin the assessment process for services or to place a person on an interest list, HHSC enters information into the intake system.



## 4. Data Analysis

HHSC analyzed the data provided by the CAQ and CSQ to establish a profile of informal caregivers in Texas. As statutorily required, the following sections discuss how HHSC will use the data to:

- Evaluate the needs of assessed informal caregivers;
- Measure the effectiveness of certain informal caregiver support interventions;
- Improve existing informal caregiver support programs;
- Develop new services for informal caregivers; and
- Determine the effect of informal caregiving on employment and employers.

### Caregiver Demographic Characteristics

The following data provides the characteristics and demographics of responding caregivers.

Of the caregivers responding to the CAQ:

- 68 percent are married
- 12 percent have children under the age of 18
- Caregivers identified as the following race/ethnicity (Figure 2):
  - 41 percent non-Hispanic Whites
  - 37 percent Hispanic
  - 20 percent Black/African Americans
  - 2 percent Asian/Other
- 95 percent of caregivers are over the age of 39 (Figure 3):
  - 48 percent are 40–64 years of age
  - 42 percent are 65–84 years of age
- The majority are the spouse or the adult child of the person they care for:
  - 38.4 percent are the spouse of the care recipient
  - 35.8 percent are the adult child of the care recipient
- 88 percent live within 10 miles of the care recipient
- 99 percent provide care at least once per week
- Almost half are caring for a person with Alzheimer's
- 64 percent are unemployed

Of the caregivers responding to the CSQ:

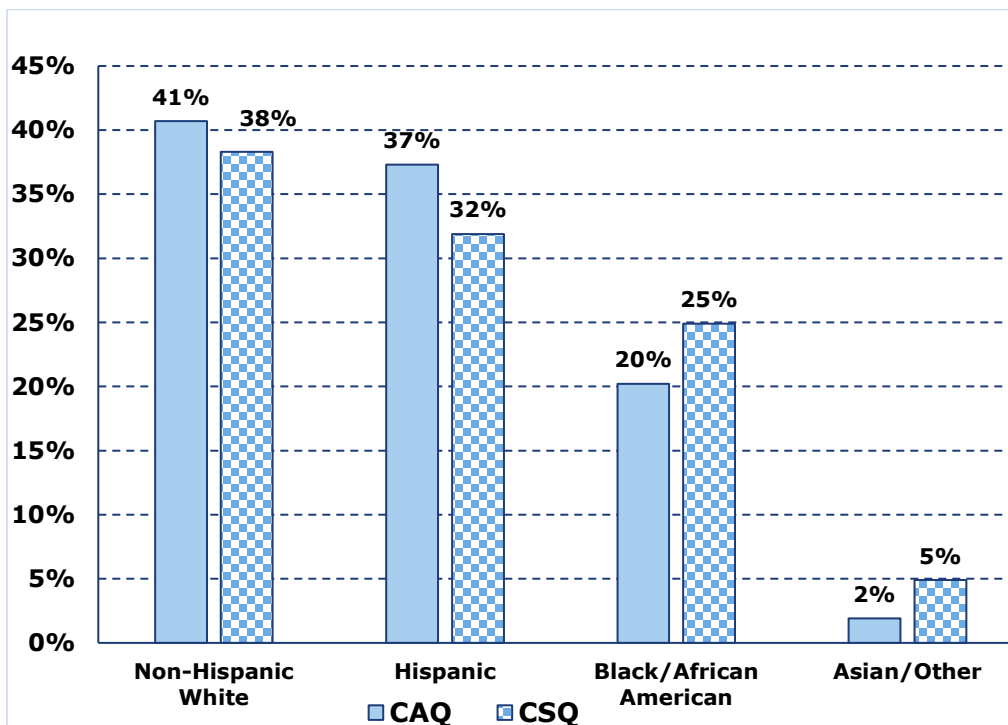
- 50 percent are married

- 25 percent have children under the age of 18
- Caregivers identified as the following race/ethnicity (Figure 2):
  - 38 percent non-Hispanic Whites
  - 32 percent are Hispanic
  - 25 percent Black/African American
  - 5 percent Asian/Other
- 77 percent of caregivers are over the age of 39 (Figure 3):
  - 59 percent are 40–64 years of age
- The majority are the spouse or the adult child of the care recipient:
  - 19.3 percent are the spouse of the care recipient
  - 48.1 percent are the adult child of the care recipient
- 91 percent live within 10 miles of the care recipient
- 99.8 percent provide care at least once per week
- 71 percent are unemployed

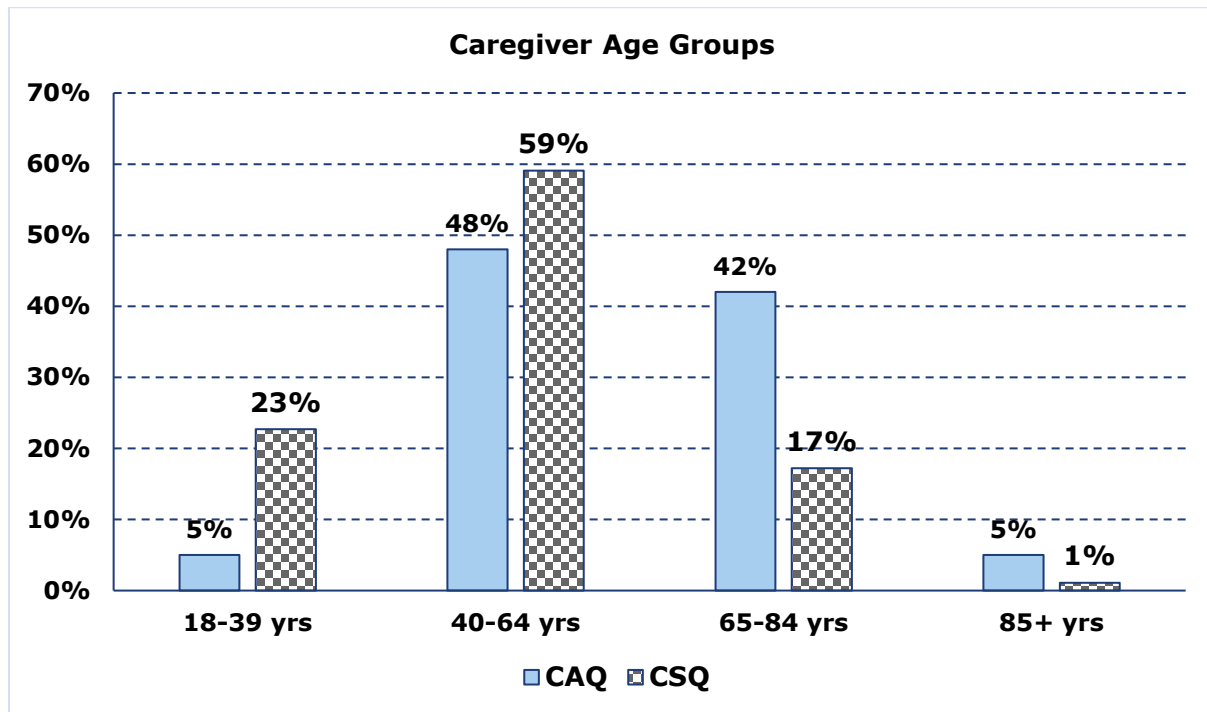
**Table 2. Familial Status of Caregivers**

| Familial Status            | CAQ | CSQ |
|----------------------------|-----|-----|
| Married                    | 68% | 50% |
| With children under age 18 | 12% | 25% |

**Figure 2. Race/Ethnicity of Caregivers**



**Figure 3. Age of Informal Caregivers**



## Caregiver Relationship to Care Recipient

Data shows informal caregivers were most often relatives of the care recipients, most of whom are a spouse or adult child. There are notable differences between CAQ and CSQ results for caregiver and care recipient relationships due to the different populations served. CAQ data is collected from caregivers of people age 60 or older, while CSQ data includes caregivers of people with disabilities who are age 59 or younger.

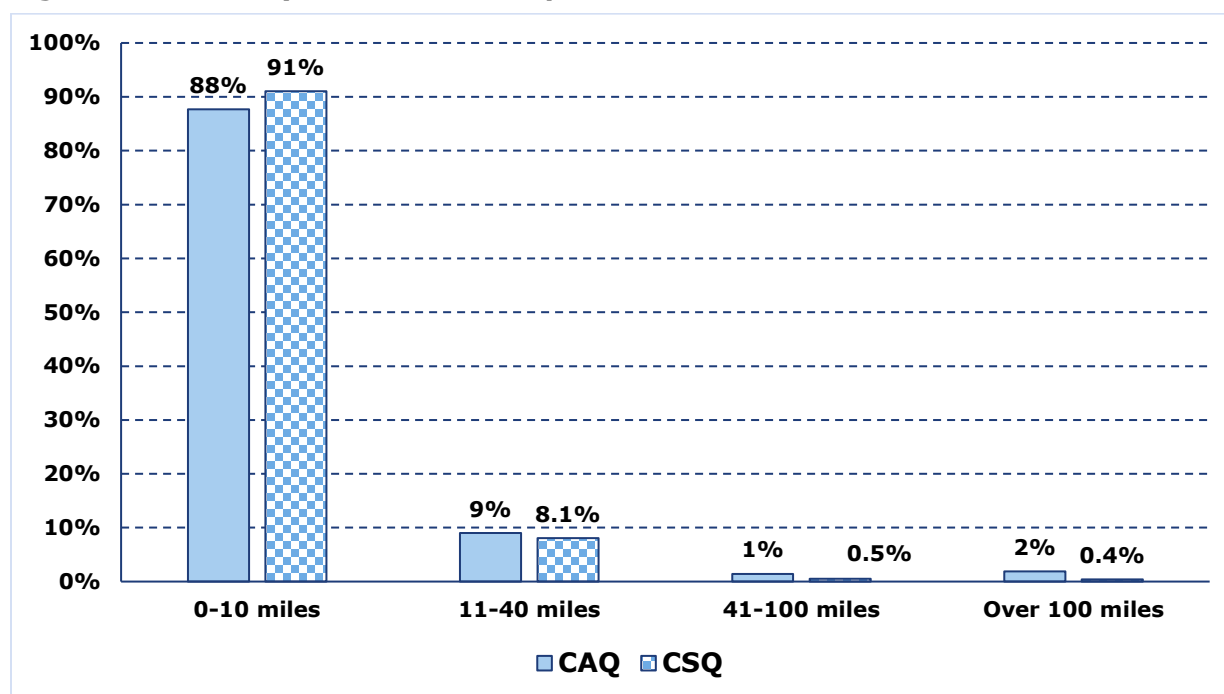
**Table 3. Relationship to Care Recipient**

| Relationship to Care Recipient                    | CAQ   | CSQ   |
|---|-------|-------|
| Spouse  | 38.4% | 19.3% |
| Adult child                                       | 35.8% | 48.1% |
| Grandparent, grandchild, life partner, sibling    | 5.9%  | 11.2% |
| Other relative                                    | 7.7%  | 9.3%  |
| Son-in-law, daughter-in-law                       | 9.2%  | 3.9%  |
| Other non-relative (i.e., friend, neighbor, etc.) | 3.0%  | 8.1%  |

## Caregiver Proximity to Care Recipient

Most caregivers reported living 0–10 miles from their care recipient on both questionnaires. Only a very small percentage of caregivers reported living over 40 miles from their care recipient (Figure 4).

**Figure 4. Proximity to the Care Recipient**



## Caregiver Time Dedicated to Assist Care Recipient

Both questionnaires examined the frequency and duration of care provided by a caregiver.

In the CAQ, 99 percent of caregiver's report providing care at least once per week. In the CSQ, 99.8 percent of caregiver's report providing care at least once per week.

CAQ data indicates the following related to the duration of care provided:

- 7.3 percent report providing care for less than one month
- 89.2 percent report providing care for at least one month and up to a year
- 5.7 percent report providing care for one to less than two years
- 2.9 percent report providing care for two to less than five years
- 1.1 percent report providing care for five or more years

CSQ data indicates the following related to the duration of care provided:

- Less than one percent report providing care for less than one month
- 37 percent report providing care for at least one month and up to a year
- 18.4 percent report providing care for one to less than two years
- 22.4 percent report providing care for two to less than five years
- 21.6 percent report providing care for five or more years

## **Caregiver Skills and Training**

Unlike the CAQ, the CSQ does not include questions assessing caregiver skills and training. Therefore, the two subsections below only include data collected from the CAQ.

### **Support Tasks Performed by Caregivers**

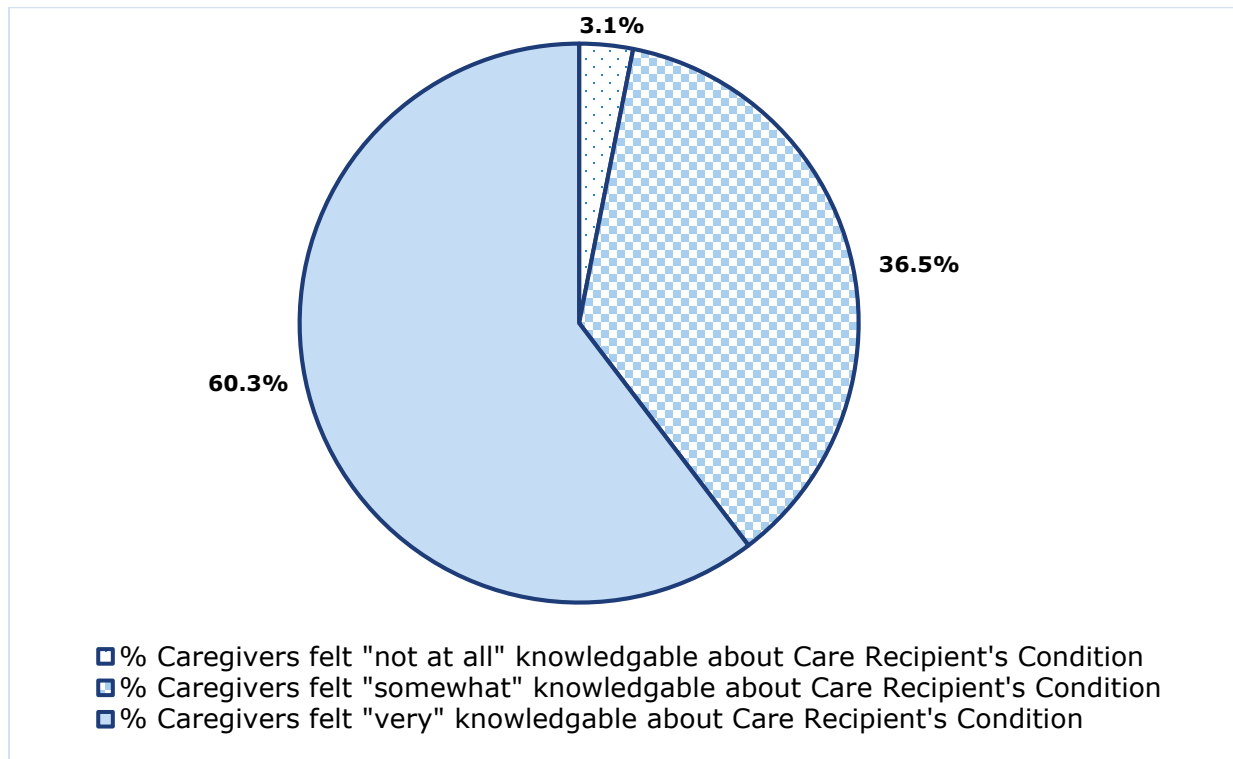
Caregivers reported a high level of responsibility in providing care for the care recipient. Of the caregiver responses, 94 percent reported the care recipient requires assistance with three or more personal care tasks, and 2 percent reported being a grandparent or older relative (age 55 or older) providing care for an adult child with a severe disability.

### **Caregiver Knowledge of Care Recipient's Condition**

Of the caregivers assessed by the AAAs, 42.3 percent care for a person with Alzheimer's disease. Of the respondents, 95 percent felt caregiving would continue indefinitely, and 22 percent believed the care recipient was at risk of institutionalization.

More than half of caregivers indicated they felt very knowledgeable about the care recipient's disease or condition. Over 36 percent reported feeling somewhat knowledgeable, and over 3 percent reported feeling not at all knowledgeable about the care recipient's disease or condition (Figure 5).

**Figure 5. CAQ Caregiver Knowledge of Care Recipient's Condition**



## Caregiver Challenges

### Caregiver's Health Impact on Caregiving

The health status of caregivers has a significant impact on their ability to provide care (Figure 6).

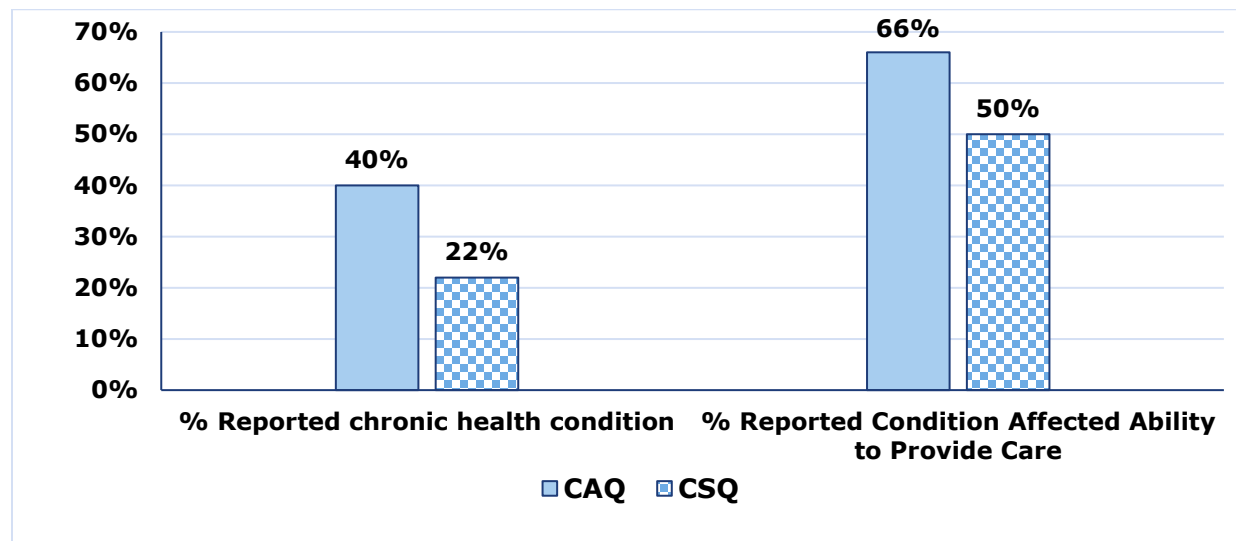
Of caregivers responding to the CAQ:

- 40 percent reported having a chronic health condition or recent health crisis
- 66 percent reported their health has affected their ability to provide care for the care recipient
- 22 percent reported the care recipient is at risk of institutionalization due to the caregiver's health problems (information not reported on CSQ)

Of caregivers responding to the CSQ:

- 22 percent reported having a chronic health condition or recent health crisis
- 50 percent reported their health has affected their ability to provide care for the care recipient

**Figure 6. Caregiver's Health Impact on Caregiving**



**Note:** The *reported condition affected ability to provide care* is based on respondents who reported having a chronic health condition.

## Caregiver Stress Levels

While many caregivers in the study feel their role has given them a sense of purpose or meaning (51 percent), these positive emotions often coexist with feelings of stress or strain.<sup>3</sup>

According to the American Association of Retired Persons (AARP), “those who have been providing care for one year or longer more often report high emotional stress (42 percent vs. 28 percent of those who have provided care for less time).”<sup>4</sup> In addition, “results suggest that the association between caregiving and mortality may not be as related to the relationship between the caregiver and care recipient or the amount of time spent providing care as it is to the perceived mental or emotional strain involved in providing care.”<sup>5</sup>

Table 4 provides data on caregiver stress levels, as reported by caregivers in both the CAQ and CSQ.

<sup>3</sup> AARP (May 2020), Caregiving in the U.S. 2020 Report, [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf)

<sup>4</sup> Ibid.

<sup>5</sup> Caregiving Strain and All-Cause Mortality: Evidence from the REGARDS Study (2013). J Gerontol B Psychol Sci Soc Sci. 2013 Jul; 68(4): 504–512.

**Table 4. Caregiver Stress Levels**

| <b>Stress Level</b> | <b>CAQ</b> | <b>CSQ</b> |
|---------------------|------------|------------|
| High                | 27.3%      | 32%        |
| Moderate            | 46.4%      | 45%        |
| Low                 | 26.3%      | 23%        |

Of caregivers responding to the CAQ:

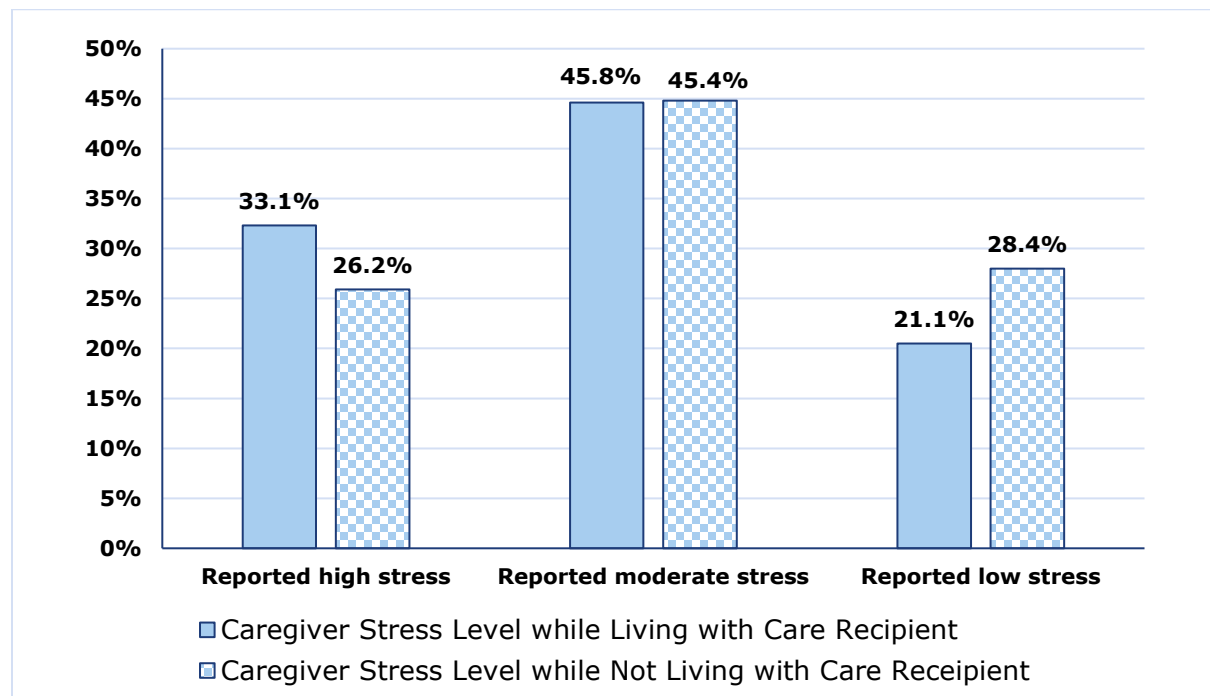
- 65.7 percent of caregivers agreed or strongly agreed that providing care while meeting other family and work responsibilities was stressful
- 86.6 percent of caregivers felt they had an obligation to provide care to the care recipient
- 42 percent reported that providing care has strained their finances.

Of caregivers responding to the CSQ (Figure 7):

- Among caregivers living with the person they care for:
  - 33.1 percent reported high stress levels
  - 45.8 percent reported moderate stress levels
  - 21.1 percent reported low stress levels
- Among caregivers who do not live with the person they care for:
  - 26.2 percent reported high stress levels
  - 45.4 percent reported moderate stress levels
  - 28.4 percent reported low stress levels



**Figure 7. CSQ Caregiver Stress Level and Proximity to Care Recipient**



Most caregivers reported they are caring for only one person.

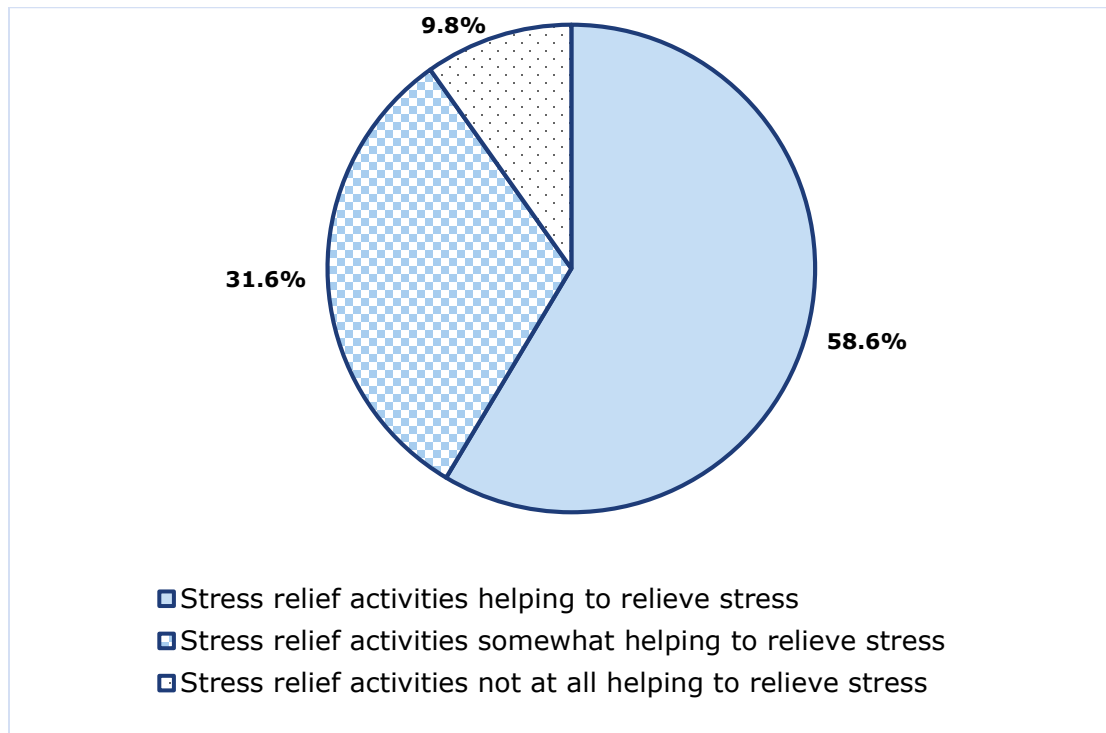
- 83 percent of CAQ caregivers and 80 percent of CSQ caregivers indicated they are providing care for only one care recipient
- 40 percent of caregivers providing care for more than one person reported high stress levels compared to 30 percent of those who provide care to only one person

In addition, over half of CAQ caregivers reported engaging in stress relieving activities (Figure 8).

- 58.6 percent reported stress relief activities were helping to relieve stress
- 31.6 percent reported stress relief activities were somewhat helping to relieve stress
- 9.8 percent reported stress relief activities not at all helping to relieve stress

**Note:** The CSQ does not include a question related to whether a caregiver engages in stress relieving activities.

**Figure 8. Stress Relief Activities, CAQ Respondents**



Despite the stress, caregivers reported feeling positive about their experience. According to CAQ findings:

- 94 percent reported a feeling of satisfaction by helping the care recipient
- 88 percent reported feeling confident about providing care
- 38 percent felt they do a better job of providing care than someone else

## **5. Effectiveness of Informal Caregiver Support Interventions**

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

The following data came from CAQ responses only, as the CSQ does not include questions relating to caregiver knowledge or acceptance of support services.

- 71 percent of caregivers were not aware of support services prior to contacting the AAA
- 76 percent had not received caregiver support services in the past
- 17 percent of caregivers reported reluctance about accepting outside help
- 8 percent of caregivers reported a lack of trust of service providers in their home
- 16 percent believed no one else could provide care as well as they do
- 95 percent reported their caregiving is likely to continue indefinitely

## 6. Effect of Informal Caregiving on Employment and Employers

According to the Pew Research Center article “5 Facts about Family Caregivers,” “Many are also juggling their own jobs with their caregiving responsibilities. Six-in-ten (61%) caregivers are employed, including nearly half who work full-time.”<sup>6</sup> In addition, “roughly half of these caregivers have been providing help for two years or less. More than a third have been providing care for five or more years.”<sup>7</sup>

Rising health care and professional caregiving costs have put increased pressure on American employees as they try to balance work and caregiving responsibilities. According to AARP, “the lack of support in the workplace has a real effect on retention and turnover – when caregivers have particular benefits at work, they are less likely to stop working altogether. Just 6 percent of caregivers with paid sick days and 6 percent of those with unpaid family leave stop working entirely (vs. 11 percent who stop working among caregivers who do not have each benefit).”<sup>8</sup>

In Texas, most employed caregivers responding to the CAQ and CSQ reported having experienced no negative impacts on their employment because of caring for another person. However, this impact might be understated, most respondents reported being unemployed (Figure 9).

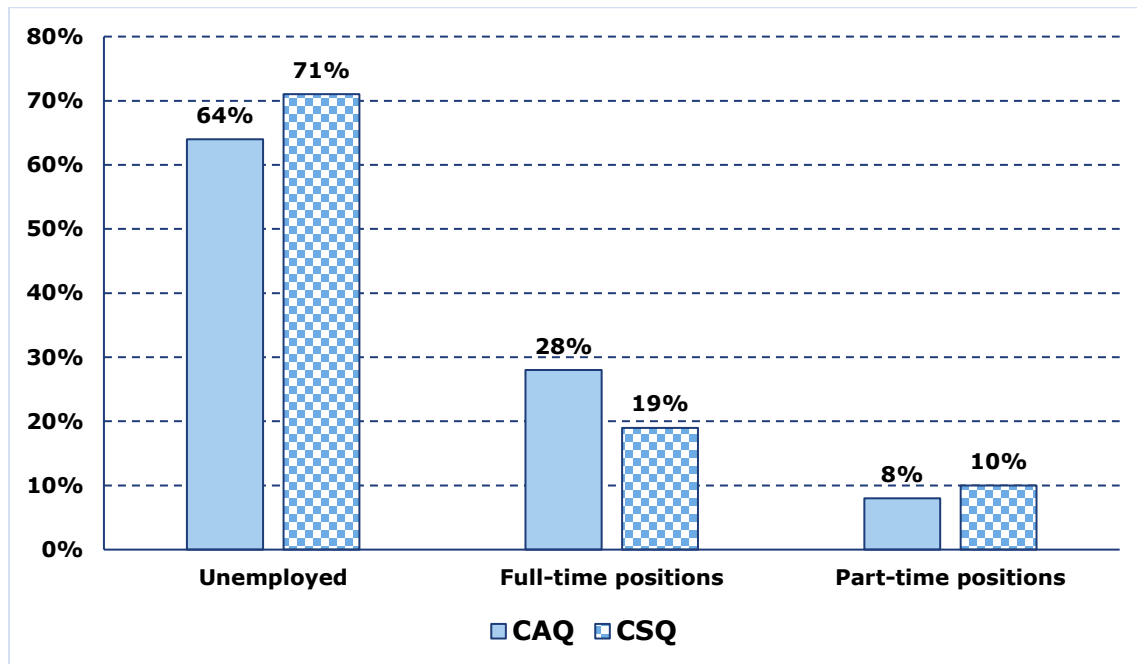
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<sup>6</sup> Pew Research Center, (November 18, 2015), *5 facts about family caregivers*.  
<http://pewrsr.ch/1MC5IxI>

<sup>7</sup> Ibid.

<sup>8</sup> AARP (May 2020), Caregiving in the U.S. 2020 Report, [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf)

**Figure 9. Caregiver Employment**

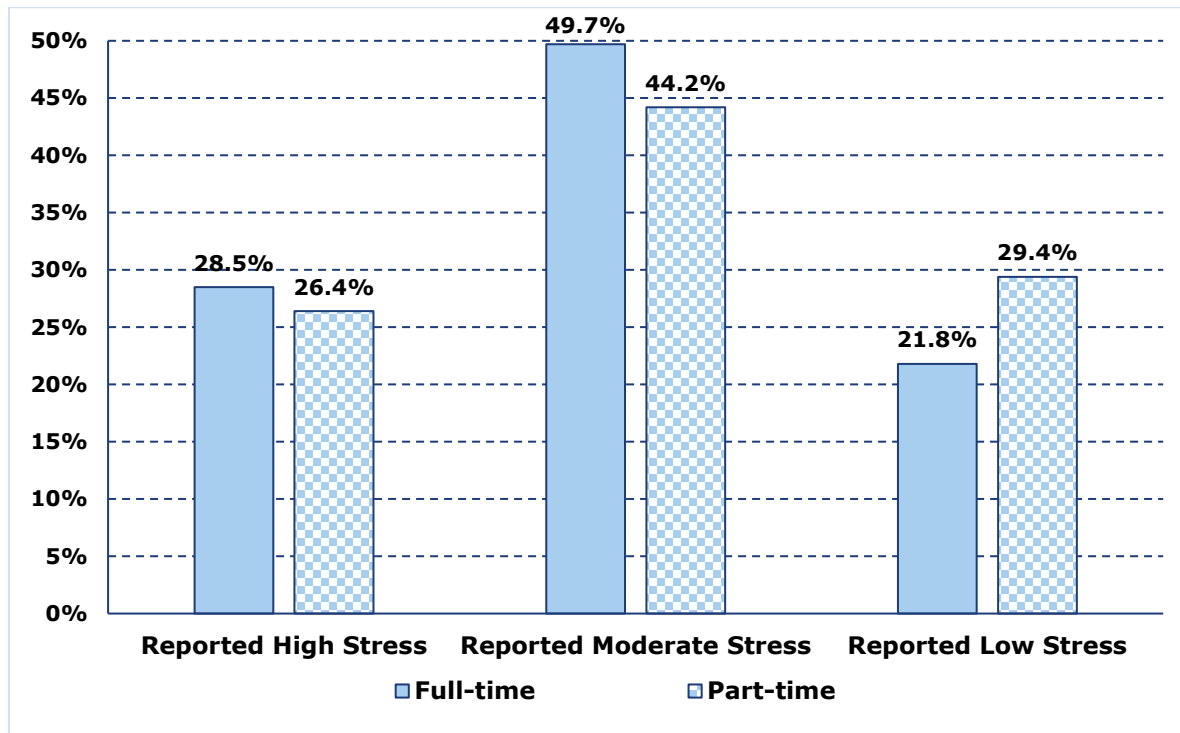


For caregivers reporting that caregiving responsibilities affected their employment, impacts include:

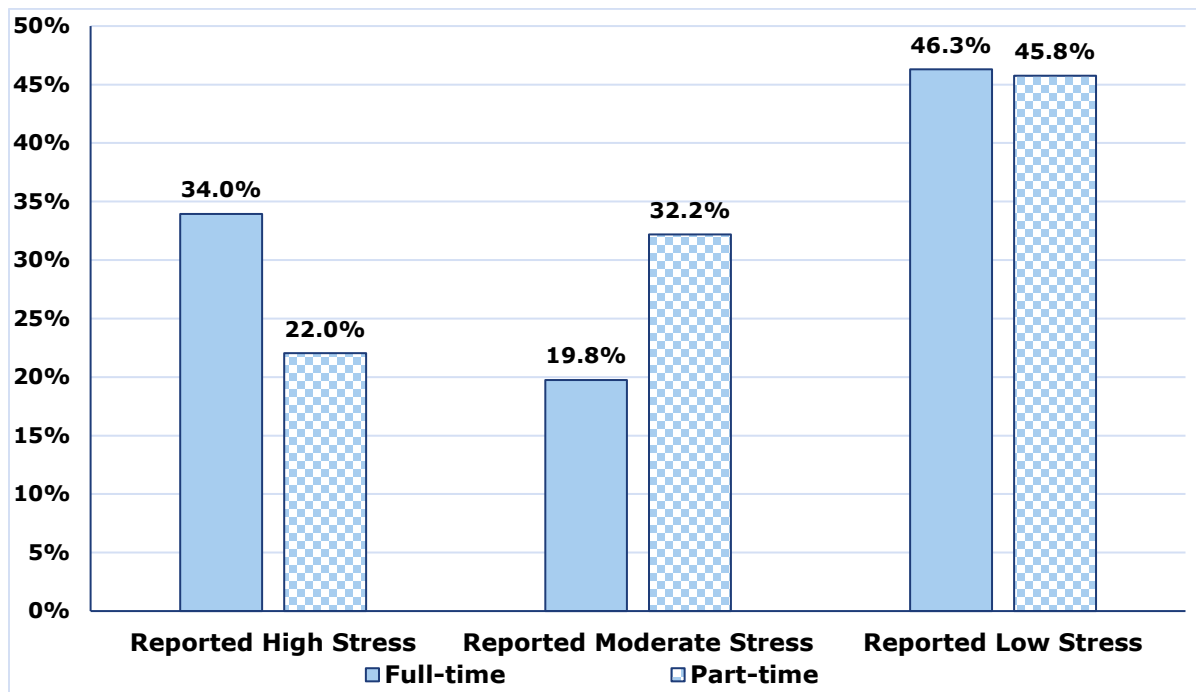
- Decreasing work hours or moving to part-time;
- Taking frequent leave;
- Losing wages or using extended leave without pay;
- Performing or managing caregiver tasks at work; and
- Difficulty focusing or concentrating at work.

Caregivers also reported fear of losing or having to quit their jobs due to increased caregiving duties, which contributes to caregiver stress (Figure 10 and Figure 11).

**Figure 10. Stress Level Correlated to Employment Level (CAQ)**



**Figure 11. Stress Level Correlated to Employment Level (CSQ)**



In addition to personal costs to the caregiver, there is a cost to employers due to absenteeism, workplace disruptions, and reduced work status. The American

workplace loses \$38.2 billion in productivity annually due to caregiving responsibilities.<sup>9</sup>

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<sup>9</sup> *Double Duty, The Caregiving Crisis in the Workplace*, Ceridian Lifework (2015).

## 7. Improvements to Caregiver Support Programs

HHSC offers a variety of services and supports for informal caregivers through the AAAs and ADRCs that positively impact the lives of the caregiver and the person receiving care, such as:

- Caregiver education, training, and awareness
- Short-term respite
- Home modifications
- Help with personal care tasks
- Homemaker chores
- Transportation
- Medication management
- Durable medical equipment
- Benefits counseling
- Emotional support
- Basic needs assistance (e.g., housing, meals, and utility assistance)

### Information Access and Referrals

Improving caregiver support programs begins with increased public awareness and access to information about respite care services and providers. The Take Time Texas website was launched in May 2012 with a grant from the U.S. Administration on Aging.

TakeTimeTexas.org hosts an inventory of respite services in Texas including the Texas Inventory of Respite Services, a searchable database of more than 1,200 respite care providers across the state. Caregivers can search for providers in their area by county, city, zip code, type of respite provided, or age group served. Although similar databases exist on a national level, this inventory is specific to Texas and includes in-home and out-of-home respite providers.

The website has undergone several updates and enhancements to improve accessibility and information for both caregivers and service providers. Visitors to the website can access caregiver education and training materials, including self-assessment tools, information on identifying and managing stress related to caregiving, disease-specific information, and educational programs. Additionally, service providers can access training and outreach materials, including posters and brochures in both English and Spanish.



From April 1, 2018, to March 31, 2020, the *Take Time Texas* website had almost 80,000 unique page views, an increase of almost 8,000 unique page views from the previous reporting period.

HHSC is also reviewing ways to improve the customer service experience during the referral and intake process and continues to reinforce to HHSC regional staff the importance of taking the required steps to complete the CSQ when a caregiver has been identified during the intake process. HHSC also continues to send resource letters to caregivers identified during the intake process, which includes a link to the *Take Time Texas* website.

Additionally, HHSC provides brochures and push cards to ADRCs to distribute during outreach and education events. These materials are also available to members of the Texas Respite Advisory Committee. The goal of these activities is to increase awareness of the *Take Time Texas* website and the Texas Lifespan Respite Care Program to assist caregivers in finding services in their communities.

### **ADRCs and Texas Lifespan Respite Care Program**

All 28 ADRCs received funding in fiscal year 2020 to implement the Texas Lifespan Respite Care Program in their communities. Services provided through the ADRCs include emergency respite, consumer-directed respite (voucher programs), caregiver education and training, and summer camps for children and youth with disabilities.

This expansion has enabled ADRCs to customize programs to meet the unique needs of their areas. Some ADRCs have used funds to train respite volunteers in rural areas in collaboration with community and faith-based organizations. Additionally, many ADRCs have collaborated with their local AAAs to provide services to caregivers on the AAAs' interest lists.

Ongoing improvements include enhancing the *Take Time Texas* website, focusing efforts on an underserved population, and expanding the capacity of ADRCs to improve caregivers' access to support services and educational opportunities, including training on personal care skills and stress reduction.

### **Consumer-Directed Care**

The consumer-directed service delivery model allows caregivers to choose a provider to meet their needs. The Caregiver Respite Care Voucher service delivery model is a consumer-directed service offered by the AAAs. This service may also help caregivers in rural counties with limited options to provider agencies.

Over the 2018–2020 biennium, people who received Caregiver Respite Care Voucher services increased by 4 percent and the total number of respite hours increased by 26 percent. Over the 2021–2022 biennium, HHSC will continue to work with AAAs to increase awareness of the Caregiver Respite Care Voucher service.

## **Evidenced-Based Interventions**

Programs, such as the Stress Busting Program for Family Caregivers<sup>10</sup> and Powerful Tools for Caregivers<sup>11</sup>, help to improve the quality of life of family caregivers by promoting self-care education, stress management and coping techniques, and use of community resources.

The Stress Busting Program for Family Caregivers has two sub-programs. The Stress Busting Program for Family Caregivers – General focuses on supporting family caregivers who provide care for people with chronic illnesses through group sessions designed to help them manage their stress and cope better with their lives. Similarly, the Stress Busting Program for Family Caregivers – Dementia is specifically designed to support family caregivers who provide care for people with Alzheimer’s disease and related dementia.

The Powerful Tools for Caregivers is a program designed to help caregivers learn how to reduce stress, improve self-confidence, manage their time, set goals, solve problems, better communicate their feelings, locate helpful resources, and make tough decisions.

Through increased outreach to informal caregivers and evidence-based intervention programs, caregivers become better equipped to provide support. HHSC and AAAs will continue to promote and expand evidenced-based interventions that support family caregivers. Over the 2018–2020 biennium, although the number of programs did not increase, the number of caregivers participating in evidence-based intervention programs increased by 68 percent when compared to the previous biennium.

In addition to evidence-based intervention programs, caregivers are supported through AAA Caregiver Education and Training. During the 2018–2020 biennium, Caregiver Education and Training participation increased by 40 percent.

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<sup>10</sup> Developed at U.T. Health Science Center, <http://www.caregiverstressbusters.org/>

<sup>11</sup> Based on the Chronic Disease Self-Management Program developed at Stanford University. <https://www.powerfultoolsforcaregivers.org/>

## **Data Collection and Analysis**

As required by statute, HHSC analyzes data collected from the CAQ and CSQ to better understand the needs of caregivers in Texas. Regularly updated data analysis of the *A Profile of Informal Caregiving in Texas* report helps inform future policy and program decisions.

In addition, HHSC compares regional needs to the resources available in the TakeTimeTexas.org inventory of respite services which allows HHSC to identify gaps in services by region or zip code to better govern policy decisions, program focus, and outreach activities.

## 8. New Services and Strategies for Caregivers

HHSC will continue work to provide new services and strategies that support informal caregivers and their support network, which include:

- Promoting increased caregiver access to practical training opportunities;
- Promoting increased caregiver awareness about evidence-based programs designed to address caregiver health and wellness, including stress relief;
- Implementing a targeted outreach plan to identify and partner with local community organizations to enhance community development and involvement;
- Promoting increased awareness and outreach to help caregivers understand how to access, apply for, understand, and receive in-home services that may be available;
- Implementing the Lifespan Respite Care Program, which is a State Program Enhancement Grant received from the Administration for Community Living, to enhance current state and local coordinated Lifespan Respite Care systems through innovative technology and concerted efforts to provide access to direct respite services, thereby increasing the total number of caregivers and families served;
- Implementing an expansion of the Asian American-focused volunteer-run respite care program by partnering with local community centers for the Asian population;
- Enhancing the *Take Time Texas* website, focusing efforts on an underserved population and expanding the capacity of ADRCs to improve caregivers' access to support services and educational opportunities, including training on personal care skills and stress reduction; and
- Disseminating findings of data analyses to stakeholders to support the development of effective local plans to serve caregivers.

## 9. Conclusion

Caregivers play a crucial role in helping the people they care for maintain their independence in the community. The caregiver may act as the main point of contact for physicians, home health providers, and other health care professionals seeking to develop a coordinated health care and supportive services plan to meet the person's needs. Informal caregivers are an invaluable asset as they enable the care recipient to continue living in their own home and remain part of their community, avoiding institutional placement and potentially higher costs.

It is important to understand the impact on caregivers, since they play a critical role in society and for those for whom they care. Through the CAQ and CSQ, caregivers reported increased stress and employment and health impacts related to their caregiving that affect their ability to provide care.

Because caregivers provide invaluable services to the care recipient, as well as society, sustaining and supporting informal caregivers must continue to be a primary topic for future policy and practice discussions. HHSC will continue to discuss:

- Increasing public awareness and access to information about respite care services and providers;
- Expanding the capacity of ADRCs to provide caregivers access to support services and educational opportunities;
- Increasing awareness of consumer-directed models of service delivery;
- Promoting evidenced-based interventions that support family caregivers;
- Improving data collection methods and analysis to better govern policy decisions, program focus, outreach activities, and future infrastructure design; and
- Adding new services to address developing issues for informal caregivers.

## **List of Acronyms**

| <b>Acronym</b> | <b>Full Name</b>                           |
|----------------|--|
| AAA            | area agency on aging                       |
| AARP           | American Association of Retired Persons    |
| ADRC           | aging and disability resource center       |
| CAQ            | Caregiver Assessment Questionnaire         |
| CSQ            | Caregiver Status Questionnaire             |
| HHSC           | Texas Health and Human Services Commission |