# Table of Contents

**Executive Summary** .............................................................................................................. 1

**Introduction** .......................................................................................................................... 2

**Background** ............................................................................................................................ 3
  Program Changes ...................................................................................................................... 5

**Data Analysis** .......................................................................................................................... 6
  Demographic Characteristics of Caregivers ............................................................................. 6
  Caregivers and Relationship to Care Recipient ................................................................. 8
  Proximity of the Caregiver to the Care Recipient ............................................................... 9
  Caregiver Time Dedicated to Assist Care Recipient ........................................................... 9
  Caregiver Skills and Training ............................................................................................... 10
  CAQ Support Tasks Performed by Caregivers ................................................................. 10
  CAQ Caregiver Knowledge of Care Recipient’s Condition ............................................. 10
  Caregiver Challenges ........................................................................................................... 11
  Caregiver’s Health Issues Impact on Caregiving .............................................................. 11
  Stress Level of Caregivers .................................................................................................... 12
  Effectiveness of Certain Informal Caregiver Support Interventions ............................... 15
  CAQ Caregiver Knowledge and Acceptance of Support Services ................................. 15
  Effect of Informal Caregiving on Employment and Employers ....................................... 15

**Improving Existing Caregiver Support Programs** ............................................................... 18
  Information Access and Referrals ......................................................................................... 18
  ADRCs and TLRCP ............................................................................................................... 19
  Consumer Directed Care ...................................................................................................... 19
  Evidenced Based Interventions .......................................................................................... 20
  Data Collection and Analysis .............................................................................................. 20
  New Services for Caregivers ............................................................................................... 21

**Conclusion** ............................................................................................................................. 22

**Appendix A. List of Acronyms** ............................................................................................ A-1

**Appendix B. S.B. 271, 81st Legislature, Regular Session, 2009** ........................................ B-1

**Appendix C. CAQ and CSQ In-depth** .................................................................................. C-1
  CAQ In-depth ....................................................................................................................... C-1
  CSQ In-depth ....................................................................................................................... C-2
Human Resources Code, Section 161.079(g) requires the Health and Human Services Commission (HHSC) to report on the strategies implemented by HHSC to collect and analyze data related to informal caregiver support services in Texas. 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 22 aging and disability resource centers (ADRCs) work to expand outreach and public awareness of services and supports available to help individuals prepare for and sustain their role as informal caregivers.

In 2012, HHSC in coordination with state programs and local providers launched 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, 2016, and March 31, 2018, HHSC interviewed 9,216 informal caregivers from HHSC community services and AAA programs. The data collected by HHSC provides further evidence that:

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

Furthermore, informal caregivers who reported full or part-time employment answered additional questions about the effects of caregiving on their employment. A small percentage reported having to quit a job due to caregiving and stress levels.
Introduction

Informal caregivers are relatives and friends who provide unpaid care to older individuals and persons with disabilities. In Texas, an estimated 3.4 million caregivers care for older Texans and persons with disabilities, enabling the person receiving care to age in place and delay the need for institutional placement.

Senate Bill (S.B.) 271, 81st Legislature, Regular Session, 2009, (Appendix B) modified the Human Resources Code and added Section 161.079. It required the legacy Department of Aging and Disability Services, now HHSC, to:

- Identify caregivers of individuals interested in accessing HHSC-administered Medicaid programs;
- Establish a standardized assessment to be used by the area agencies on aging (AAA), to evaluate the needs of caregivers of individuals who are eligible to receive Older Americans Act (the Act) services; and
- Utilize 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:

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


Based on the 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.
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, taking medication, and may also help manage appointments with doctors and provide or arrange transportation. Many Texans are unprepared to assume the role of caregiver when the time comes. Helping Texans prepare for and sustain their roles as caregivers has a positive impact on the individuals giving and the individual receiving care. Additionally, this assistance helps the state avoid long-term services and supports (LTSS) costs that might otherwise be billed to Medicaid.

House Bill (H.B.) 802, 81st Legislature, Regular Session, 2009, created the lifespan respite care program, and S.B. 271 directed state agencies to identify caregivers and improve the delivery of caregiver support services in Texas by:

- Raising public awareness about caregiving and available support services;
- Implementing a caregiver status form into the existing Medicaid functional eligibility determination process;
- Standardizing a caregiver assessment and protocol for caregivers accessing services through a AAA; and
- Analyzing quantitative data collected from the informal caregivers.

Additionally, Congress recognized the need to support family caregivers by passing the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act in January 2018. The RAISE Family Caregivers Act requires the U.S. Secretary of Health and Human Services to develop, maintain, and update an integrated national strategy to support family caregivers.

HHSC uses the Caregiver Assessment Questionnaire (CAQ) and the Caregiver Status Questionnaire (CSQ) to assess caregiver needs. These surveys are used to determine placement of care-recipients on program interest lists or a care plan for services (Fig. 1).

- Local AAAs complete a CAQ for all caregivers receiving caregiver support funded through Title III-E of the Older Americans Act to identify the caregiver’s needs and services.
- HHSC Community Services regional intake staff use the CSQ to determine eligibility for Social Security Title XX programs and provide a profile of the
caregivers for referrals to HHSC programs, AAAs, and other state or community agencies.

**Figure 1 - Caregiver Assessment Tools**

- **Caregiver Assessment Questionnaire**
  - Used by Area Agencies on Aging
  - For clients of Older Americans Act Title III E Services
  - Collects caregiver demographic and needs data
  - Includes caregiver well-being questions

- **Caregiver Status Questionnaire**
  - Used by HHSC Regional Staff
  - Part of the intake process for HHSC community services programs
  - Identifies informal caregivers for referrals
  - Collects caregiver demographic data
**Program Changes**

Since the last reporting period, changes in programs administering the CSQ impacted the number of interviews (Table 1).

- Effective November 1, 2016, the Medically Dependent Children Program, which used the CSQ, transitioned to STAR Kids and clients were moved to a managed care provider.
- The 84th Texas Legislature did not appropriate funds for the In-home and Family Support Program. As a result, the program ended effective September 1, 2017, reducing the number of CSQ respondents.

There were 58.41 percent less CSQ interviews during the current reporting period of April 1, 2016, through March 31, 2018, compared to the last reporting period of April 1, 2014, through March 31, 2016.

**Table 1 - Number of CAQ and CSQ Interviews**

<table>
<thead>
<tr>
<th>Survey Period</th>
<th>CAQ</th>
<th>CSQ</th>
<th>Total Number of Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>April 1, 2016 through March 31, 2018</td>
<td>6,311</td>
<td>2,905</td>
<td>9,216</td>
</tr>
<tr>
<td>April 1, 2014 through March 31, 2016</td>
<td>5,743</td>
<td>6,985</td>
<td>12,728</td>
</tr>
<tr>
<td>Percent Change</td>
<td>9.89%</td>
<td>-58.41</td>
<td>-27.59%</td>
</tr>
</tbody>
</table>
**Data Analysis**

HHSC analyzed the data provided by the CAQ and CSQ interviews to establish a profile of informal caregivers in Texas. 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.

**Demographic Characteristics of Caregivers**

Respondents made up the following demographics:

Caregivers responding to the CAQ:
- 71 percent are married
- 87 percent have no children under the age of 18
- Caregivers identified as the following race/ethnicity
  - 44 percent non-Hispanic Whites
  - 37 percent Hispanic
  - 18 percent Black/African Americans
- The majority are the spouse or the child of the person they care for
  - 41.2 percent are the spouse of the recipient
  - 33.8 percent are the child of the recipient
- 87 percent live within 10 miles of the person they care for
- 99 percent provide care at least once per week
- Almost half are caring for a person with Alzheimer’s
- 65 percent are unemployed

Caregivers responding to the CSQ:
- 49 percent are married
- 74 percent have no children under the age of 18
- 77 percent over the age of 39
- Caregivers identified as the following race/ethnicity
  - 37 percent are Hispanic
  - 36 percent non-Hispanic Whites
- 26 percent Black/African American
- 1 percent Asian, American Indian/Alaskan Natives and Native Hawaiian, or Other Pacific Islanders

- The majority are the spouse or the child of the person they care for
  - 19.4 percent are the spouse of the recipient
  - 47.7 percent are the child of the recipient

- 91 percent live within 10 miles of the person they care for
- 96 percent provide care at least once per week
- 71 percent are unemployed

**Table 2 - Familial Status of Caregivers**

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>CAQ</th>
<th>CSQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>71%</td>
<td>49%</td>
</tr>
<tr>
<td>No Children under Age 18</td>
<td>87%</td>
<td>74%</td>
</tr>
</tbody>
</table>

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

![Race/Ethnicity of Caregivers](chart)
Caregivers and Relationship to Care Recipient

Data shows informal caregivers were most often relatives of the care recipients. A majority of whom were children or a spouse. There are notable differences between CAQ and CSQ results for caregiver and care recipient relationships because of the different populations served. CAQ data is collected from caregivers of individuals 60 years and older, while CSQ data includes caregivers of individuals with disabilities who are younger than 60.

Table 3 - Relationship to the Care Recipient

<table>
<thead>
<tr>
<th>Relationship</th>
<th>CAQ</th>
<th>CSQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>41.3%</td>
<td>19.4%</td>
</tr>
<tr>
<td>Child</td>
<td>33.9%</td>
<td>47.7%</td>
</tr>
<tr>
<td>Grandparent/Grandchild/Life Partner/Sibling</td>
<td>6.4%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Other Relative</td>
<td>7.1%</td>
<td>9.5%</td>
</tr>
</tbody>
</table>
## Proximity of the Caregiver to the Care Recipient

The majority of caregivers reported living 0-10 miles from their care recipient on both surveys, as outlined in Figure 4. Only a very small percentage of caregivers reported living over 40 miles from their care recipient.

![Figure 3 - Proximity to the Care Recipient](image)

### Caregiver Time Dedicated to Assist Care Recipient

Both assessments examined the frequency and length of time spent on caregiving activities.
Table 4 - Caregiver Frequency of Caregiving Activities

<table>
<thead>
<tr>
<th>Caregivers</th>
<th>CAQ</th>
<th>CSQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide care at least once per week</td>
<td>99%</td>
<td>99%</td>
</tr>
<tr>
<td>Have someone to call in emergency</td>
<td>85%</td>
<td>47%</td>
</tr>
</tbody>
</table>

CSQ data also indicated:

- Seven percent reported providing care for less than one month
- 83 percent reported providing care for at least one month and up to a year
- Six percent reported providing care for one to two years
- Three percent reported providing care for two to five years
- Less than one percent reported 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.

**CAQ Support Tasks Performed by Caregivers**

Caregivers reported a high level of responsibility in providing care for the recipient.

- 92 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

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

Almost half of the caregivers assessed by AAAs care for a person with Alzheimer’s disease, 96 percent of respondents felt caregiving would continue indefinitely, while 23 percent believe 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. Thirty-five percent reported feeling somewhat knowledgeable and two percent reported feeling not at all knowledgeable about the care recipient’s disease or condition (Fig. 5).
Caregiver Challenges

Caregiver’s Health Issues Impact on Caregiving

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

Caregivers responding to the CAQ:
- 44 percent reported having a chronic health condition or recent health crisis
- 32 percent stated their health has affected their ability to provide care for the care recipient
- 23 percent reported the care recipient is at risk of institutionalization due to the caregiver’s health problems

Caregivers responding to the CSQ:
- 22 percent reported having a chronic health condition or recent health crisis
- 48 percent stated their health has affected their ability to provide care for the care recipient
Figure 6 – Caregiver’s Health Issues Impact on Caregiving

<table>
<thead>
<tr>
<th>Stress Level</th>
<th>CAQ</th>
<th>CSQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>27%</td>
<td>32%</td>
</tr>
<tr>
<td>Moderate</td>
<td>44%</td>
<td>45%</td>
</tr>
<tr>
<td>Low</td>
<td>29%</td>
<td>23%</td>
</tr>
</tbody>
</table>

Caregivers responding to the CAQ:
- 63 percent of caregivers agreed or strongly agreed providing care while meeting other family and work responsibilities was stressful
- 87 percent of caregivers felt they had an obligation to provide care to the care recipient.

Caregivers responding to the CSQ (Fig. 7):
- Among caregivers living with the person they care for
  - 34 percent reported high stress levels
  - 45 percent reported moderate stress levels
  - 22 percent reported low stress levels
- Among caregivers who do not live with the person they care for
  - 26 percent reported high stress levels
  - 47 percent reported moderate stress levels
  - 27 percent reported low stress levels

Figure 7 – CSQ Caregiver Stress Level and Proximity to Care Recipient

Most caregivers reported they were not providing care to more than one person.
- 80 percent of CAS and CSQ caregivers indicated they were not providing care to anyone other than the care recipient
● 41 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

Meanwhile, over half of caregivers reported engaging in stress relieving activities (Fig 8).

● 58 percent reported engaging in effective activities to relieve stress
● 34 percent reported their activities were “somewhat” effective
● 9 percent reported finding no effective ways to relieve their stress

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

However, caregivers reported feeling positive about their experience. According to CAQ findings:

● 92 percent reported a feeling of satisfaction by helping the care recipient
● 87 percent reported feeling confident about providing care
● 37 percent felt do a better job of providing care than someone else
● While 40 percent reported that providing care strained their finances
Effectiveness of Certain Informal Caregiver Support Interventions

CAQ Caregiver Knowledge and Acceptance of Support Services

- 69 percent of caregivers were not aware of support services prior to contacting the AAA
- 73 percent had not received caregiver support services in the past
- 11 percent of caregivers reported reluctance about accepting outside help
- 7 percent of caregivers reported a lack of trust of service providers in the home
- 18 percent believed no one else could provide care as well as they do
- 60 percent had other concerns about receiving caregiver support
- 96 percent reported their caregiving is likely to continue indefinitely

Effect of Informal Caregiving on Employment and Employers

According to the Families and Work Institute report 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.”2 This becomes even more significant in light of the National Alliance for Caregiving and MetLife Mature Market Institute’s *Study of Caregiving Costs to Working Caregivers*, which states: “The total estimated aggregate lost wages, pension, and Social Security benefits of these caregivers of parents is nearly $3 trillion.”3

In Texas, most employed caregivers surveyed with the CAQ and CSQ reported they have experienced no negative impacts on their employment because of

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providing care to another person. This impact might be understated as a majority of respondents reported that they were unemployed (Fig. 9).

- 71 percent of CSQ respondents reported being unemployed
- 65 percent of CAQ respondents reported being unemployed

**Figure 9 - Caregiver Employment**

![Caregiver Employment Chart]

For caregivers reporting that caregiving responsibilities affected their employment, impacts include decreasing work hours or going 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 jobs due to increased caregiving duties. These impacts contribute to the caregiver stress challenges discussed (Table 6).

**Table 6 - Stress Level Correlated to Employment Level**

<table>
<thead>
<tr>
<th>Employment Level</th>
<th>High-Stress</th>
<th>Moderate Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time</td>
<td>33%</td>
<td>48%</td>
</tr>
<tr>
<td>Part-time</td>
<td>21%</td>
<td>46%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>35%</td>
<td>44%</td>
</tr>
</tbody>
</table>

In addition to the personal costs to the caregiver, there is a cost to employers because of 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.\textsuperscript{4}

Improving Existing Caregiver Support Programs

HHSC offers a variety of supports for informal caregivers through the AAAs and ADRCs that positively impact the lives of the caregiver and the individual receiving care.

- 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 increasing public awareness and access to information about respite care services and providers.

The Take Time Texas website launched in May 2012 with a grant from the U.S. Administration on Aging to meet requirements under S.B. 271 and H.B. 802 from the 81st Legislature. 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. Although similar databases exist on a national level, this inventory is specific to Texas and includes in-home and out-of-home respite providers. Caregivers can search for providers in their area by county, city, zip code, type of respite provided, or age group served.

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. Between April 1, 2016, and
March 31, 2018, there were over 72,000 unique page views of the Take Time Texas website.

HHSC is also reviewing ways to improve the customer service experience during the referral and intake process. HHSC sends 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 the ADRCs to distribute during outreach and education events. These materials are also available to members of the Texas Respite Advisory Committee. The goal is to increase awareness of the Take Time Texas website and the Texas Lifespan Respite Care Program (TLRCP), to assist caregivers in finding services in their communities.

**ADRCs and TLRCP**

All 22 ADRCs received funding in fiscal year 2018 to implement the TLRCP in their communities. Services provided through ADRCs include emergency respite, consumer-directed respite (voucher programs), caregiver education and training, and summer camps for children and youth with disabilities. This expansion 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 collaborated with their local AAAs to provide services to caregivers on the AAA’s waitlist.

Ongoing improvements will include expanding the capacity of ADRCs to improve caregivers’ access to support services and educational opportunities, including training on personal care skills, caring for individuals with dementia, and stress reduction. Other potential improvements to ADRC services include options counseling, evidence-based disease prevention and health promotion interventions.

**Consumer Directed Care**

Consumer-directed and/or voucher models of service delivery allow caregivers to choose a provider to meet their needs. This may also help 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.”

Over the 2019-2020 biennium, HHSC will work with AAAs to expand consumer-directed models.

**Evidenced Based Interventions**

Programs such as the Stress Busting Program for Family Caregivers and Powerful Tools for Caregivers 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 has group sessions specifically designed for family caregivers who provide care for persons with Alzheimer’s disease and related dementia. 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.

**Data Collection and Analysis**

HHSC analyzes data collected from the CAQ and CSQ for a better understanding about the needs of the caregivers in Texas. Regularly updated data analysis of the profile of Texas caregivers helps inform future policy and program decisions at HHSC. As a result of this current analysis, the report workgroup identified changes to current intake processes needed to improve data collection and analysis of the profile of caregivers across Texas. Changes to be made include:

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6 Developed at U.T. Health Science Center, http://www.caregiverstressbusters.org/

7 Based on the Chronic Disease Self-Management Program developed at Stanford University, https://www.powerfultoolsforcaregivers.org/
• Improving data collection methods to ensure additional data is captured in future samples;
• Change open-ended questions to closed-ended questions on both the CAQ and CSQ to refine the responses;
• Review the CSQ with intake staff and reaffirm the importance of correctly completing the CSQ when it is applicable and appropriate.

In addition, HHSC program staff regularly collect data from other systems that support long-term care services and supports. Comparing regional needs to the resources available in the inventory of respite services will allow HHSC to identify gaps in services by region or zip code to better govern policy decisions, program focus, and outreach activities.

**New Services for Caregivers**

HHSC is working to provide new services that will support informal caregivers and their support network. These services include:

• Promoting increased caregiver access to “hands-on” practical training opportunities;
• Implementing 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;
• Implementing 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.
• Disseminating findings of data analyses to stakeholders to support the development of effective local plans to serve caregivers.
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 because 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 because of the critical role they play in society. Through the CAQ and CSQ surveys, caregivers report increased stress and employment and health impacts related to their caregiving that affect their ability to provide care.

Because caregivers provide invaluable service to the person receiving care as well as society, sustaining and supporting informal caregivers should 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;
- Expanding consumer-directed models of service delivery;
- Promoting and expanding 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.
### Appendix A. List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAA</td>
<td>Area Agency on Aging</td>
</tr>
<tr>
<td>ADRC</td>
<td>Aging and Disability Resource Center</td>
</tr>
<tr>
<td>CAQ</td>
<td>Caregiver Assessment Questionnaire</td>
</tr>
<tr>
<td>CSQ</td>
<td>Caregiver Status Questionnaire</td>
</tr>
<tr>
<td>H.B.</td>
<td>House Bill</td>
</tr>
<tr>
<td>HHSC</td>
<td>Health and Human Services Commission</td>
</tr>
<tr>
<td>LTSS</td>
<td>Long-term Services and Supports</td>
</tr>
<tr>
<td>OMB</td>
<td>Office of Management and Budget</td>
</tr>
<tr>
<td>RAISE</td>
<td>Recognize, Assist, Include, Support and Engage</td>
</tr>
<tr>
<td>S.B.</td>
<td>Senate Bill</td>
</tr>
<tr>
<td>TLRCP</td>
<td>Texas Lifespan Respite Care Program</td>
</tr>
</tbody>
</table>
AN ACT

relating to informal caregiver support services and to the appointment of a successor
guardian for certain wards adjudicated as totally incapacitated.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Subchapter D, Chapter 161, Human Resources Code, is amended by
adding Section 161.076 to read as follows:

Sec. 161.076. INFORMAL CAREGIVER SERVICES.

(a) In this section:

(1) "Area agency on aging" has the meaning assigned by Section 161.075.

(2) "Local entity" means an area agency on aging or other entity that provides
services and support for older or disabled persons and their caregivers.

(b) The department shall coordinate with area agencies on aging and, to the extent
considered feasible by the department, may coordinate with other local entities to
coordinate public awareness outreach efforts regarding the role of informal caregivers
in long-term care situations, including efforts to raise awareness of support services
available in this state for informal caregivers.

(c) The department shall perform the following duties to assist a local entity with
outreach efforts under this section:

(1) Expand an existing department website to provide a link through which a local
entity may post and access best practices information regarding informal
caregiver support; and

(2) Create a document template that a local entity may adapt as necessary to
reflect resources available to informal caregivers in the area supported by the
entity.

(d) The department shall create or modify a form to be included in the functional
eligibility determination process for long-term care benefits for older persons under
the Medicaid program and, to the extent considered feasible by the department, may include a form in systems for other long-term care support services. The department shall use the form to identify informal caregivers for the purpose of enabling the department to refer the caregivers to available support services. The form may be based on an existing form, may include optional questions for an informal caregiver, or may include questions from similar forms used in other states.

(e) The department shall coordinate with area agencies on aging and, to the extent considered feasible by the department, may coordinate with other local entities to develop and implement a protocol to evaluate the needs of certain informal caregivers. The protocol must:

1. Provide guidance on the type of caregivers who should receive an assessment; and

2. Include the use of a standardized assessment tool that may be based on similar tools used in other states, including the Tailored Caregiver Assessment and Referral process.

(f) The department shall require area agencies on aging and, to the extent considered feasible by the department, other local entities to use the protocol and assessment tool under Subsection (e) and report the data gathered from the assessment tool to the department.

(g) The department shall analyze the data reported under Subsection (f) and collected from the form under Subsection (d) and shall submit a report not later than December 1 of each even-numbered year to the governor and the Legislative Budget Board that summarizes the data analysis.

(g-1) Notwithstanding Subsection (g), the department shall submit the initial report required by that subsection not later than December 1, 2012. This subsection expires January 1, 2013.

(h) The department shall use the data analyzed under Subsection (g) to:

1. Valuate the needs of assessed informal caregivers;

2. Measure the effectiveness of certain informal caregiver support interventions;

3. Improve existing programs;
(4) Develop new services as necessary to sustain informal caregivers; and

(5) Determine the effect of informal caregiving on employment and employers.
Human Resources Code, Section 161.079(g) required a standardized caregiver assessment and protocol for caregivers accessing services through an AAA. Since 2010, the 28 AAAs in Texas use 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 Act defines a caregiver as “an adult family member, or another person, who is an informal provider of in-home and community care to an older person”. An older relative caregiver is defined as “a grandparent, step-grandparent or other older relative of a child, or a relative of a child by blood, marriage, or adoption, who is 55 years of age or older and lives with the child; is the primary caregiver; and has a legal relationship to the child, or is raising the child informally.”

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, but does not ask for the caregiver’s age. The relational categories included in Table 3 are the categories included in both the CAQ and CSQ and changes to those categories are being considered.

CAQ data also helps identify caregivers meeting the Older Americans Act priority populations, as well as target 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

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who completed the CSQ and were subsequently referred to the AAA by the regional intake office.

An individual, or another person contacting the AAA on behalf of an individual, may request caregiver support services by telephone, mail, email, fax, or in person. 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 completes the CAQ and enters the information into the State Unit on Aging Programs Uniform Reporting System (SPURS) using a specialized data entry format.

**CSQ In-depth**

The CSQ identifies and collects information pertaining to primary informal caregivers in response to Human Resources Code, Section 161.079(g) requirement 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 an individual of any age with Alzheimer's disease or dementia.

An individual 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 individual. Depending on the program, individuals 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 individual 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 individuals on an interest list, HHSC enters information into the client intake system.

C-2