



# **Informal Care in Texas:**

## **Aging Family Caregivers and their Need for Services and Support**

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**Prepared by:**

Texas Department of Aging and Disability Services  
Center for Policy and Innovation  
Policy Analysis and Support Unit

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## Executive summary

The Texas Department of Aging and Disability Services (DADS) recognizes the vital importance of informal or family caregiving to the broader system of long-term services and supports in Texas and throughout the nation. Without the daily efforts of these unpaid caregivers, many individuals would be unable to remain in their own homes and communities, many others would find themselves without the minimal support needed for basic safety, and the state would incur significantly higher costs in attempting to meet their needs through increased caseloads and requests for services.

This report, *Informal Care in Texas: Aging Family Caregivers and their Need for Services and Support*, discusses the significant role played by these family caregivers, and also provides information on the specific needs of this caregiver population, particularly as they are themselves aging. The recommendations presented are the result of a series of stakeholder focus groups held around the state by the Texas Department on Aging (TDoA) in 2004. Although five years old, this stakeholder information adds an important caregiver perspective on informal care in Texas, and helps document the current and future needs of this vital population of aging caregivers.

Highlights from this report include:

- Of the 34 to 44 million informal caregivers throughout the United States, approximately 2.7 million are in Texas.
- Nationally, 13 percent of individuals who provide informal care for older adults are themselves age 65 or older, and as a caregiver ages, the total number of hours they spend providing care tends to increase.
- Significant social, emotional, physical and financial effects can negatively affect those providing informal care, all of which are influenced by the level of need, presence of a support network, geography, and other factors.
- Texas' age 60 and older population is expected to increase by nearly 50 percent between 2010 and 2040, with a greater than 50 percent increase in those aged 85 and older by 2020.
- Informal care in Texas has been valued at almost \$26 billion annually, higher than total Medicaid expenditures statewide.
- During Texas' 81st Legislature (2009), bills passed that are significant to caregivers and those they care for include:
  - HB 802 creates the Lifespan Respite Services Program;
  - SB 271 relates to informal caregiver assessment and support;
- In September 2009, DADS received a grant from AoA to support and expand these respite access efforts.

Stakeholder recommendations include:

- Increasing public awareness of informal caregiving and the current services and supports available for caregivers.
- Organizing and coordinating resources and program development to further support caregivers with an emphasis on 'aging' and 'kinship' caregivers.
- Identifying and resolving gaps in supports and services to caregivers, specifically highlighting formal services as a complementary support to informal services.
- Involving stakeholder groups (employers, local community, medical professions, and others) in addressing gaps in services, supports, and incentives to support caregivers.
- Addressing the unique needs of 'kinship' caregivers who are raising grandchildren and relatives under age 18.

# Introduction

*“There are only four kinds of people in the world – those who are caregivers, those who were caregivers, those who will be caregivers, and those who will need care.”*

Rosalynn Carter,  
Former first lady of the United States,  
Board president of the Rosalynn Carter Institute for Caregiving

Informal caregivers, those relatives and friends who provide unpaid care to disabled and older individuals, are considered the backbone of the long-term care system.<sup>1</sup> In recognition of the importance of informal care to the growing aging and disabled populations in Texas, the Texas Department of Aging and Disability Services (DADS) undertook an examination of caregiver supports in order to identify the needs of aging caregivers and grandparents who are caregivers. A series of focus groups involving caregivers, service providers, and other community stakeholders were held throughout the state. These meetings sought to obtain information on the needs of informal caregivers, the services available to them, their general level of access to those services, and any significant gaps in that system of services and supports. Preceded by an overview of caregiving in Texas and a discussion of the national and state infrastructure of long-term services and supports, stakeholder recommendations from these focus groups have been analyzed and grouped for inclusion in this report.

The National Family Caregiver Support Program (NFCSP) within the federal Department of Health and Human Services’ Administration on Aging (AoA) provides grants to state agencies, based on their share of the population aged 70 and older, to fund (through Area Agencies on Aging) a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. Executive Order RP-42, the Aging Texas Well Mandate, dated April 1, 2005, requires a review of state policy by DADS, with the advice of the Aging Texas Well Advisory Committee, that concentrates on current critical trends, including improving services and supports for informal caregivers of family members or loved ones.<sup>2</sup> In direct response to the NFCSP Executive Order RP-42 signed by Gov. Rick Perry, this report seeks to identify what Texas can do to better support informal caregivers, thus encouraging and allowing them to provide necessary services in the home for as long as possible.

The Older Americans Act (OAA) defines a caregiver as “an adult family member, or another individual, who is an informal provider of in-home and community care to

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1 Texas Department of Aging and Disability Services. (2005). *Aging Texas Well: State of Our State 2005*. Retrieved July 13, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/atw\\_results\\_report.pdf](http://www.dads.state.tx.us/news_info/publications/studies/atw_results_report.pdf)

2 Texas Department of Aging and Disability Services (2008) *Aging Texas Well Plan, 2008-2009* Retrieved July 13, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/atwplan-20082009.pdf](http://www.dads.state.tx.us/news_info/publications/studies/atwplan-20082009.pdf)

an older individual...<sup>3</sup> 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.”<sup>4</sup> While there can be several definitions and many different profiles of relative or family caregivers, this report focuses primarily on caregivers who are themselves aging, whether they are caring for an elderly relative or friend or are a grandparent caring for a grandchild.

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3 Older Americans Act of 1965, 42 U.S.C. § 3022. Retrieved July 13, 2009 from [www.gpoaccess.gov/USCODE/index.html](http://www.gpoaccess.gov/USCODE/index.html)

4 Older Americans Act of 1965, 42 U.S.C. § 3030s. Retrieved July 13, 2009 from [www.gpoaccess.gov/USCODE/index.html](http://www.gpoaccess.gov/USCODE/index.html)

## Informal caregiving – an overview

While caregivers are a diverse group, this report will focus on informal caregivers who are themselves aging. Informal caregivers provide unpaid, voluntary care and assistance for family members and others. They may be spouses, adult children, friends, neighbors, parents or grandparents of those receiving care. By providing assistance with daily activities such as meal preparation, bathing and dressing, taking medication, transportation, shopping, and more, informal caregivers supply much of the support that enables individuals to remain in their own homes. With an estimated 2.7 million informal caregivers across the state of Texas<sup>5</sup>, and between 34 and 44 million informal caregivers throughout the United States, the roles that informal caregivers play are important not only to the individuals for whom they provide care, but also to the overall economy of the state and the nation.

Informal caregivers are typically between the ages of 45 and 64 and the majority of caregivers are female.<sup>6</sup> Approximately one in three caregivers has children under the age of 18 at home, and more than half (51 percent) are employed outside the home. According to the National Alliance for Caregiving, the typical caregiver is “a 46-year-old woman caring for her widowed mother who does not live with her. She is married and employed.”<sup>7</sup>

Nationally, 13 percent of caregivers assisting older adults are themselves aged 65 or over. About one-quarter of those are caring for a spouse.<sup>8</sup> Half of all caregivers provide assistance with at least one activity of daily living; 26 percent perform 3 or more of these activities, and 80 percent provide assistance with activities like shopping, meal preparation, and housework.<sup>9</sup> Of those caring for someone who is age 65 or older, the average age of the caregiver is 63 years, with one-third of these caregivers in fair to poor health, making it likely the caregivers themselves will at some point become recipients of care.<sup>10</sup> The majority of caregivers (58 percent) have been providing care for five years or less and 32 percent of caregivers provide care for more than 40 hours a week.

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5 National Family Caregiver Alliance. (2007). *State of the States in Family Caregiver Support, State Profile: Texas*. Retrieved July 23, 2009, from [www.caregiver.org/caregiver/jsp/content/pdfs/state\\_profile\\_tx.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/state_profile_tx.pdf)

6 U.S. Department of Health and Human Services. (1998). *Informal Caregiving – Compassion in Action*. Retrieved July 13, 2009, from <http://aspe.hhs.gov/daltcp/Reports/carebro2.pdf>

7 National Alliance for Caregiving and AARP. (2004). *Caregiving in the U.S.* Retrieved July 13, 2009, from [www.caregiving.org/data/04finalreport.pdf](http://www.caregiving.org/data/04finalreport.pdf)

8 Ibid.

9 US Department of Health and Human Services (n.d.). *National Clearinghouse for Long Term Care: Glossary*. Retrieved July 13, 2009, from [www.longtermcare.gov/LTC/Main\\_Site/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/index.aspx)

10 National Alliance for Caregiving and AARP. (2004). *Caregiving in the U.S.* Retrieved July 13, 2009, from [www.caregiving.org/data/04finalreport.pdf](http://www.caregiving.org/data/04finalreport.pdf)

Further compounding the issues, as caregivers age, the average number of hours they spend caregiving tends to increase (see Figure 1<sup>11</sup>).

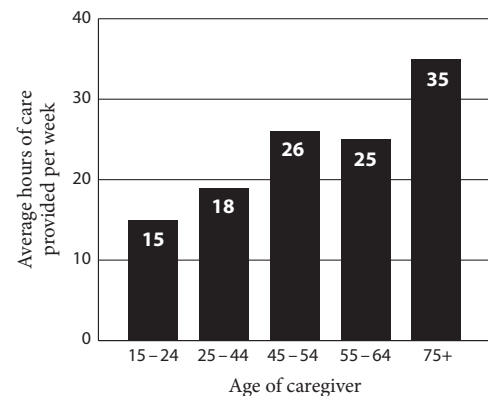
In Texas, approximately 17 percent of those responding to the 2008 Aging Texas Well Indicators Study are currently providing care to a family member or friend over the age of 60, a child 18 years of age or younger, or both.<sup>12</sup> Of those 17 percent, more than 95 percent are caring for a spouse or other family member, one-third have been a caregiver for more than 10 years, and more than one-third report providing full-time care (more than 40 hours per week). A specific breakdown of this data appears in Figure 2<sup>13</sup>.

### Caregiver shortage

Researchers believe that changes in the family structure may lead to fewer caregivers for millions of the aging Baby Boomer generation, those individuals born between 1946 and 1964. Measured by statistical norms, many of this generation's marriages have come later than those of their parents, ended sooner, and resulted in fewer births.<sup>14</sup> This generation has a divorce rate of 14.2 percent, more than twice the 6.7 percent rate of their parents.

Greater numbers of women in the workforce have created further changes in the family structure. An estimated 19 percent of women now in their early 40s have no children,<sup>15</sup> leaving them fewer options for potential family caregivers when they are needed later in life. The increase in the number of single and married adults not having children will directly affect future caregiver shortages in the absence of spouses and adult children. The result will be a significant increase in the number of individuals requiring formal community and institutional services at younger ages.

**Figure 1<sup>11</sup>**  
**Number of hours dedicated to caregiving by age of family caregiver**



**Figure 2<sup>13</sup>**  
**Characteristics of older Texas caregivers**

**Relationship of caregiver:**

Spouse	39%
Family member	57%
Friend	2%
Other	1%

**Length of time as caregiver:**

Less than 1 year	6%
1 - 5 years	41%
5 - 10 years	20%
More than 10 years	33%

**Time spent (weekly) in caregiving:**

0 - 8 hours	22%
9 - 20 hours	22%
21 - 40 hours	17%
41 hours or more	39%

11 Partnership for Solutions. (2002). *Chronic conditions: Making the case for ongoing care*. Baltimore, MD: Johns Hopkins University.

12 Texas Department of Aging and Disability Services. (2009). *Aging Texas Well Indicators Survey, Overview Report, 2009*. Retrieved July 13, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/ATWIndicators2009.pdf](http://www.dads.state.tx.us/news_info/publications/studies/ATWIndicators2009.pdf)

13 Ibid.

14 Neal, M.B. & Wagner, D.L. (2002). *Working Caregivers: Issues, Challenges, and Opportunities for the Aging Network*. Department of Health and Human Services, Administration on Aging. Washington, D.C.

15 Ibid.

Those who do have children face different challenges. Families move more than they once did, and adult children often live more than an hour from older relatives who need care.<sup>16</sup> It is estimated that there are approximately 5-7 million “long-distance caregivers” in the United States – generally caring for a relative who lives more than one hour away.<sup>17</sup> Nearly one-quarter of older caregivers in Texas report living more than 50 miles away from those to whom they provide care.<sup>18</sup> Greater numbers of single-parent households and an increase in blended families consisting of stepchildren and stepparents raises the question of whether individuals who divorced and remarried will receive the same support from stepchildren as those whose families remained intact. Smaller, increasingly fragmented families and the prospect of record numbers of individuals needing assistance create the potential for a considerable shortage of family caregivers over the next several decades.

## Challenges of caregiving

According to the Aging Texas Well Indicators Study, about 15 percent of older caregivers in Texas pay someone else to help them care for their loved one, and only six percent receive payment for the care they provide.<sup>19</sup> While informal caregiving reduces financial demands on the health care system, it can have high physical and mental costs for the caregiver. Negative effects to a caregiver can include physical strain, emotional stress, and sacrifices in work, financial, and personal activities.

The physical demands of providing care often include lifting and turning, bedding changes, bathing, and assistance moving the care recipient from their bed to a chair. Caregivers report more overall health problems (e.g., arthritis, insomnia, diabetes, obesity, weight gain) than non-caregivers.<sup>20</sup> Since beginning caregiving, more than 80 percent say their sleeping is worse, more than 60 percent report their eating habits are worse, and seven out of 10 caregivers report not going to the doctor as often as they should.<sup>21</sup> One caregiver participant in a focus group had this to say about the importance of self-care for caregivers:

*“Running yourself right down to the last point, and you have got to take care of yourself, because if you don’t and you are the one that’s taking care of your family or your group, when you are down nobody else is going to handle it.”*

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16 Ibid.

17 Wagner, D.L. (1997) *Long-Distance Caregiving for Older Adults*. Healthcare and Aging. National Council on the Aging. Washington, D.C.

18 Texas Department of Aging and Disability Services. (2009). *Aging Texas Well Indicators Survey, Overview Report, 2009*. Retrieved July 13, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/ATWIndicators2009.pdf](http://www.dads.state.tx.us/news_info/publications/studies/ATWIndicators2009.pdf)

19 Ibid.

20 Shultz, R. O’Brien, A. Bookwala, J. and Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, Correlates, and Causes. *The Gerontologist*, 35, 771-791.

21 National Alliance for Caregiving and Evercare. (2006). *Evercare Study of Caregivers in Decline*. Retrieved August 10, 2009, from [www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf](http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf)

*You have to get the right amount of rest and take care of your physical and emotional needs and, if nothing else, just get out and look up and holler, 'God, give me the grace to carry one more day.'"*

Emotional demands are also high, placing caregivers at risk for depression, stress, exhaustion, and fatigue.<sup>22</sup> Caregiver stress is often brought on by the disruption of life and lifestyle, feelings of greater responsibility for another person, as well as guilt and frustration associated with unmet expectations. Caregivers experience pressures from decision-making and role conflict, and can become isolated from family and friends.<sup>23</sup> Nearly 55 percent of caregivers reported having less time for family members, and have sacrificed vacations, leisure time, and/or hobbies.<sup>24</sup>

Depression appears to be the most common psychological disorder, with between 20 and 50 percent of caregivers reporting depressive disorders or symptoms, with the higher levels of depression mostly attributed to those who care for individuals with dementia.<sup>25</sup> Studies have also shown a higher rate of prescription and psychotropic drug use among caregivers, and that stress in family caregivers is inversely correlated to income: the less income a caregiver has, the more stress he or she is likely to experience.<sup>26</sup> After sending her loved one to adult day care, a participant in another focus group had this realization regarding the emotional challenges she faced as a caregiver:

*"I sent him five days a week and didn't realize how bad off I really was, because I went through a serious depression after he came out here and had some real difficulties."*

Financial sacrifices for those providing care can take a significant toll. According to a 2007 survey by the National Alliance for Caregiving, caregivers spend an average of \$5,500 a year as part of their responsibilities, not counting lost wages.<sup>27</sup> The recent economic decline has only made an already difficult situation worse for many caregivers, care receivers, and their families. In a recent article in the New York Times,<sup>28</sup>

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22 Family Caregiver Alliance, National Center on Caregiving. (2001, October). *Who Will Provide Care? Emerging Issues for State Policy Makers*. Proceedings of the Family Caregiver Alliance National Invitational Conference, San Francisco, CA.

23 Ibid.

24 Tennstedt, S.L. (1999, March). *Family Caregiving in an Aging Society*. Paper presented at the U.S. Administration on Aging Symposium: Longevity in the New American Century, Baltimore, MD.

25 National Family Caregiver Alliance. (n.d.) *Selected Caregiver Statistics*. Retrieved July 13, 2009, from [www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=439](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439)

26 Ibid.

27 National Alliance for Caregiving and Evercare. (2009). *The Evercare Survey of The Economic Downturn and its Impact on Family Caregiving*. Retrieved on July 13, 2009, from [www.caregiving.org/data/EVC\\_Caregivers\\_Economy\\_Report%20FINAL\\_4-28-09.pdf](http://www.caregiving.org/data/EVC_Caregivers_Economy_Report%20FINAL_4-28-09.pdf)

28 Leland, John. (2009). Downturn Puts a Chokehold on Those Caring for Family Members. *The New York Times*, 6/7/09, A16. Retrieved July 13, 2009, from [www.nytimes.com/2009/06/07/us/07squeeze.html](http://www.nytimes.com/2009/06/07/us/07squeeze.html)

the authors make the point that the current economic conditions have taken an increased toll on those caring for family members. Loss of income, whether voluntary or not, has elevated the everyday stresses of those providing care and those receiving it. In the recent Evercare/National Alliance for Caregiving (NAC) survey, one in six said they had lost a job during the downturn, and 21 percent said they had to share housing with family members to save money.<sup>29</sup> Another NAC survey, conducted in conjunction with AARP, reported that nearly 60 percent of caregivers currently work either full- or part-time while providing care. Additionally, more than 60 percent report that their caregiving responsibilities have affected their work.<sup>30</sup>

Many focus group participants had personal experiences that bear witness to those national statistics. One woman described the stark choices caregivers face when working outside the home means their loved one is alone:

*“...and there were times when I was working...so he was there by himself all day. I felt guilty and I quit I don’t know how many jobs, and he’s been with us seven years.”*

Another caregiver spoke to the challenge of finding a new job that would be compatible with her role as a caregiver:

*“I do it all and had to quit my job about three years ago to take care of her. It’s hard to find jobs now, even though her health is better...I might have to leave work at the drop of a hat to go pick Mother up off the floor or whatever, because she has fallen a lot. Well, employers don’t really want to deal with that, so it has been hard finding a job and finances have been hard and emotionally it has been very hard.”*

The effects of caregiving on those providing care can differ dramatically with respect to their family member or friend’s disability or medical condition. The functional level of the care recipient, the amount of time devoted to caregiving, and the presence of a support network also affect the caregiver. The needs of the care recipient, as well as those of the caregiver, are certain to change over time. All of these factors can influence the caregiver’s level of stress and burden, and ultimately affect the caregiver’s need for supportive services. Additional factors, such as financial resources, geographic proximity to service providers, education, and awareness of available support, further affect the caregiver’s ability to access those services.

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29 National Alliance for Caregiving and Evercare. (2009). *The Evercare Survey of The Economic Downturn and its Impact on Family Caregiving*. Retrieved on July 13, 2009, from [www.caregiving.org/data/EVC\\_Caregivers\\_Economy\\_Report%20FINAL\\_4-28-09.pdf](http://www.caregiving.org/data/EVC_Caregivers_Economy_Report%20FINAL_4-28-09.pdf)

30 National Alliance for Caregiving and AARP. (2004). *Caregiving in the U.S.* Retrieved July 13, 2009 from [www.caregiving.org/data/04finalreport.pdf](http://www.caregiving.org/data/04finalreport.pdf)

# National and state infrastructure: A Texas perspective

Projections by the Social Security Administration suggest 20 percent of Americans will be aged 65 or older by the year 2030. That same group comprised only about 12 percent of the population in 2006.<sup>31</sup> In Texas, between 2010 and 2040, the population aged 60 and older is expected to increase from 3.7 million to 9.4 million, an expansion of almost 50 percent.<sup>32</sup> Increased longevity is also expected to result in an expansion by more than 50 percent in the number of Texans age 85 and older by 2020. Since family caregivers are the greater part of the long-term care system in America, this expected significant increase in the population of older individuals raises concerns about the ability of informal caregivers to continue to fill this role.

Informal care is estimated to be worth almost three times the cost of formal, publicly funded care. With as many as 44 million family caregivers in the United States, the annual value of unpaid care in 2007 was approximately \$375 billion.<sup>33</sup> In Texas alone, that value comes to nearly \$26 billion, which is greater than the total state Medicaid expenditures, and more than five times the spending for Medicaid on long-term care.<sup>34</sup>

In the absence of a comprehensive national system of long-term services and supports, many states have developed their own systems, primarily funded by Medicaid and state general revenues.<sup>35</sup> Texas faces a growing need for these services and supports due to a rapidly growing aging population, changes in social infrastructure that limit the number and availability of informal caregivers, consumer preference for home and community-based services, and mounting constraints on state and federal resources, most notably Medicaid.

Texas policymakers have focused on creating a system of supports that will enable and encourage informal caregivers to sustain their caregiving role longer and maintain a healthy balance in their own lives. Supports for caregivers include respite services, information and assistance, education and training, and counseling. These supports are provided through a variety of sources, such as Area Agencies on Aging (AAAs)

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31 AgingStats.gov: Federal Interagency Forum on Aging-related Statistics. (2008). *Older Americans 2008: Key Indicators of Well-Being*. Retrieved July 13, 2009, from [www.agingstats.gov/Agingstatsdotnet/Main\\_Site/Data/2008\\_Documents/Population.aspx](http://www.agingstats.gov/Agingstatsdotnet/Main_Site/Data/2008_Documents/Population.aspx)

32 Texas Department of Aging and Disability Services. (2007). *Texas State Plan on Aging, 2008-2010*. Retrieved July 13, 2009, from [www.dads.state.tx.us/news\\_info/publications/planning/stateplanonaging/2008-2010/stateplan2008-2010.pdf](http://www.dads.state.tx.us/news_info/publications/planning/stateplanonaging/2008-2010/stateplan2008-2010.pdf)

33 AARP Public Policy Institute. (2008). *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*. Retrieved July 14, 2009 from [http://assets.aarp.org/rgcenter/il/i13\\_caregiving.pdf](http://assets.aarp.org/rgcenter/il/i13_caregiving.pdf),

34 Ibid.

35 Feinberg, L.F, Newman, S.L., Gray, L. & Kolb, K.N. (2004, November) *The State of the States in Family Caregiver Support: A 50-state study*. Family Caregiver Alliance, San Francisco, CA.

and their networks, community social services, state-funded respite services programs, Medicaid Personal Care services, Medicaid home- and community-based service waiver programs, and volunteer networks.

Most caregivers continue to face considerable demands on their time and finances that threaten their willingness and capacity to continue to assume most of the responsibility for the care of their loved one. Unchecked, these demands could result in caregivers' inability to maintain their roles, producing a further decline in the availability of informal care. This resulting shortfall would have significant financial and programmatic implications for the state in its efforts to provide a system of long-term services and supports.

## **The Older Americans Act**

The Older Americans Act (OAA) was signed into law by President Lyndon B. Johnson in 1965, and has served as the primary vehicle for providing and coordinating community-based services for older Americans and their families. In its Declaration of Objectives, the OAA states that older adults should have “opportunities for a comprehensive array of community-based long term care services adequate to sustain people in their communities and in their homes, including support to family members and other persons providing voluntary care to older individuals needing long-term care services.”<sup>36</sup>

OAA programs include services targeted at low-income minorities, in-home services for frail elderly, and services that protect the rights of older individuals, such as the long-term care ombudsman program. These programs support the nearly 38 million Americans who are age 65 or older,<sup>37</sup> including approximately 5.5 million Americans aged 85 and older – many of whom live alone without caregivers, live in institutional settings, suffer mental and physical impairments, have low income, or live in rural areas with limited access to services and supports.

The OAA established the U.S. Administration on Aging within the Department of Health and Human Services.<sup>38</sup> The OAA also authorized grants to states for community planning and service programs, and for research, demonstration and training projects in the field of aging. Subsequent amendments provided grants to AAAs for local needs identification, planning, and funding of services, including nutrition programs, services for low-income minority elders, health promotion and disease prevention activities, and long-term care ombudsman programs to protect the rights of older individuals.

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36 Older Americans Act of 1965, 42 U.S.C. § 3001. Retrieved July 14, 2009, from [www.gpoaccess.gov/USCODE/index.html](http://www.gpoaccess.gov/USCODE/index.html)

37 U.S. Department of Health and Human Services, Administration on Aging. (2008). *A Profile of Older Americans: 2008*. Retrieved July 14, 2009, from [www.aoa.gov/AoARoot/Aging\\_Statistics/Profile/2008/docs/2008profile.pdf](http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2008/docs/2008profile.pdf)

38 Ibid.

In 2000 and 2006, the OAA was reauthorized with several amendments signed into law. One of the most significant developments from the 2000 amendments was the creation of the National Family Caregiver Support Program (NFCSP), “designed to assist the hundreds of thousands of family caregivers of older loved ones who are ill or who have disabilities”.<sup>39</sup> Recognizing family members as the predominant caregivers among non-institutionalized individuals needing assistance with activities of daily living, Congress in 2006 allocated \$155 million to the NFCSP for grants to state agencies on aging. This represented an increase of \$30 million over previous funding years.<sup>40</sup> The program called for state agencies on aging to work with AAAs and community and service organizations to provide support services to family caregivers. Also under the fiscal 2000 amendments, states and AAAs were granted greater flexibility in developing comprehensive, coordinated service systems.

In 2006, the OAA definition of “caregiver” was expanded to include those caring for older individuals with Alzheimer’s disease.<sup>41</sup> This and other 2006 amendments allowed AAAs to continue to provide services and supports, while consolidating and streamlining many AAA programs. The amendments retained the provisions for low-income members of minority groups, individuals living in rural areas, and added a focus for individuals with limited English proficiency. The amendments also retained priority services, thereby emphasizing access, in-home, and legal services.<sup>42</sup> The 2006 reauthorization of the OAA supports the NFCSP’s continued mission of supporting the growing needs of aging caregivers.

## **The National Family Caregiver Support Program**

The bulk of public caregiver supports comes from the NFCSP, which explicitly addresses the information and service needs of caregivers, allowing states to establish or build on existing caregiver support programs. Like many other states without existing official programs for informal or family caregivers, Texas utilized the NFCSP funding to develop infrastructure to support them.

The NFCSP calls for states, working in partnership with AAAs and local community service providers, to offer five basic services for family caregivers:

1. Information to caregivers about available services,
2. Assistance to caregivers in gaining access to supportive services,

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39 U.S. Department of Health and Human Services, Administration on Aging. (2009). *National Family Caregiver Support Program Fact Sheet*. Retrieved July 14, 2009, from [www.aoa.gov/AoARoot/Press\\_Room/Products\\_Materials/pdf/fs\\_NationalFamilyCaregiver.doc](http://www.aoa.gov/AoARoot/Press_Room/Products_Materials/pdf/fs_NationalFamilyCaregiver.doc)

40 Generations United. (2007). *Fact Sheet-Grandparents and other Relatives Raising Grandchildren: Their Inclusion in the NFCSP*. Retrieved July 14, 2009, from [www.gu.org/documents/A0/NFCSP\\_2007.pdf](http://www.gu.org/documents/A0/NFCSP_2007.pdf)

41 U.S. Department of Health and Human Services, Administration on Aging. (n.d.). *Outline of 2006 Amendments to the Older Americans Act*. Retrieved July 14, 2009, from [www.aoa.gov/AoARoot/AoA\\_Programs/OAA/oa\\_change.aspx?id=2](http://www.aoa.gov/AoARoot/AoA_Programs/OAA/oa_change.aspx?id=2)

42 Ibid.

3. Individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles,
4. Respite services to temporarily relieve caregivers of their responsibilities, and
5. Supplemental services, on a limited basis, to complement the care provided by caregivers.<sup>43</sup>

The intent of the NFCSP is to provide a range of services that best meet the needs of family caregivers while providing adequate flexibility through the supplemental service category. Eligible populations include family caregivers of older adults (age 60 and older) and individuals with Alzheimer's disease, and grandparents and relative caregivers of children not more than 18 years of age. Under the NFCSP, states are required to give priority consideration to individuals in greatest social and economic need (with particular attention to low-income, minority individuals), and older individuals providing care and support to individuals with mental retardation and related developmental disabilities.<sup>44</sup>

In accordance with the OAA, eligibility for services under NFCSP programs is typically limited to family caregivers of older individuals determined to be frail either because of inability to perform unassisted at least two activities of daily living, or need for substantial supervision because of cognitive or other mental impairment. In addition, supplemental services such as personal assistance or homemaker services that may be available under this program may not supplement or duplicate any formal or informal services already in place for the care recipient.

## **Area Agencies on Aging**

Under the federal OAA, AAAs are administratively responsible for the development of a comprehensive and coordinated system of services for the population aged 60 and older. This includes serving as a centralized location for caregiver services and supports through the Family Caregiver Support Program. The purpose of the program is to educate, support, and empower caregivers who care for individuals aged 60 and older or individuals with disabilities.

Texas has 28 AAAs throughout the state that deliver a range of services to individuals aged 60 and older. While DADS provides statewide oversight and support for the AAAs, each AAA functions independently to identify specific local needs and develop innovative approaches to service delivery. AAAs are managed locally throughout the state; they are not entities of DADS, nor are their staff state employees. Within each service area, the AAAs plan, coordinate, and advocate for a comprehensive service-delivery system to address the short- and long-term needs of older Texans.

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43 U.S. Department of Health and Human Services, Administration on Aging. (2009). *National Family Caregiver Support Program Fact Sheet*. Retrieved July 14, 2009, from [www.aoa.gov/AoARoot/Press\\_Room/Products\\_Materials/pdf/fs\\_NationalFamilyCaregiver.doc](http://www.aoa.gov/AoARoot/Press_Room/Products_Materials/pdf/fs_NationalFamilyCaregiver.doc)

44 Ibid.

The heart of the service network is an all-inclusive system of access and assistance. This key role is designed to help older individuals, their family members, and caregivers more easily obtain services and information. Whether consumers need general information, advice on government benefits, ombudsman services, legal assistance, service authorization or care coordination for individuals who need numerous services, AAAs either directly provide information and services or refer individuals to an appropriate resource. Access and assistance services provided by the AAAs (directly and through contractor and vendor agreements) help individuals receive the information and assistance they need to obtain resources.

In Texas, AAAs also provide a broad system of supports for caregivers (the Appendix details caregiver supports provided through AAAs). Most AAAs employ full-time caregiver specialists who are responsible for disseminating information about available resources and coordinating access to services and supports. AAAs rely heavily on the support of local community partnerships and a network of volunteers to meet the needs of a growing and diverse client base. They also play a critical role in coordinating caregiver support in Texas and in helping develop the infrastructure necessary to meet the needs of the growing population of caregivers across the state.

In House Bill 802, 81st Legislature, Regular Session, 2009, Texas legislators created and funded the Lifespan Respite Services Program within DADS. Largely a service facilitation and coordination effort, this program seeks to support caregivers through connecting them to respite providers in their communities, voucher provision (to those not eligible for other respite services), and public awareness activities regarding available respite services. In addition, in September 2009, DADS received a \$200,000 grant from AoA to support and expand these respite access efforts through the creation of a Texas Respite Coalition Coordination Center.

In further support to caregivers, Senate Bill 271, 81st Legislature, Regular Session, 2009, requires DADS to coordinate public outreach efforts regarding the role of informal caregivers in long-term care situations with AAAs (and other local entities). Under this law, DADS is also required to incorporate the identification of informal caregivers into its functional eligibility determination process for long-term care under Medicaid and to refer those identified to available support services. DADS is further directed to develop and implement a standardized assessment tool to evaluate the needs of informal caregivers who access local services. Data gathered from these assessments will be reported to the governor and the Legislative Budget Board beginning in 2012.

In fiscal 2008, AAA service providers in Texas reached an estimated audience of almost 13 million with information services related to caregiver services and provided access assistance to more than 14,000 caregivers (estimated). They accomplished the delivery of services ranging from counseling and training to respite through a network of more than 600 service providers throughout the state. Further detail and expenditures for each service area can be seen in Figure 3.

**Figure 3<sup>45</sup>**

**AAA support services for caregivers serving older individuals and children in Texas (fiscal 2008)**

	Title III-E expenditures (federal \$)	Total service expenditures (all sources)	Number of caregivers served (unduplicated)	Number of providers (unduplicated)
Counseling/ support groups/ caregiver training	\$674,055	\$898,740	3,388	29
Respite care	\$2,273,041	\$2,851,264	3,157	350
Supplemental services	\$1,675,686	\$2,182,318	5,425	261
Access assistance	\$1,871,195	\$2,373,893	14,137*	39
Information services	\$1,093,284	\$1,437,536	12,904,508**	187
<b>Totals (unduplicated)</b>	<b>\$7,587,261</b>	<b>\$9,743,751</b>		<b>666</b>

Source: DADS Access and Intake Unit, AAA Section

\*estimated unduplicated number of caregivers

\*\*estimated audience size

**Medicaid and more**

Medicaid is the federal-state assistance program in which medical bills are paid from federal and state tax funds. It serves low-income individuals of every age. Individuals who are older or who have a disability and need help with daily activities may be able to receive services in their homes, thus relieving some of the burden on family caregivers. Programs vary from state to state, and are run by state and local governments within the established federal guidelines.

Texas' Medicaid program is administered by the Texas Health and Human Services Commission (HHSC), in collaboration with DADS. Within DADS, the Access and Intake Division establishes and oversees the state's service system, including OAA programs and intellectual and developmental disabilities services. DADS regional and local field offices are responsible for determining functional eligibility for Medicaid and programs funded by the Title XX Social Services Block Grant. These field offices contract with providers at the regional level to administer Medicaid programs. Medicaid waiver programs include, but are not limited to, Community-Based Alternatives, Community Living Assistance and Support Services, Deaf-Blind with Multiple Disability Waiver program, Consolidated Waiver Program, Home and Community-Based Services, and Personal Assistance Services. The Medicaid community entitlement programs include Primary Home Care, Community Attendant Services, and Day Activity and Health Services. The DADS Reference Guide provides

45 Ibid.

more detail on the various community programs, both Medicaid and non-Medicaid, that DADS administers.<sup>46</sup>

In addition to OAA-funded and Medicaid services, Texas offers several other complementary programs that round out its continuum of services and supports for individuals with disabilities and older Texans. While several of these programs are institutional in nature, many directly address the needs of those choosing to stay in their home and community settings, and thus positively support those providing informal care. These services include, but are not limited to, Adult Foster Care, Consumer Managed Personal Attendant Services Program, Day Activity and Health Services, Emergency Response Services, Family Care, and In-Home and Family Support.

Despite the ever-widening range of services throughout Texas that provide support to informal caregivers, systemic challenges remain. Caregivers are a demographically diverse group, particularly in a state as varied as Texas. As a part of the process of improving the caregiver support system in Texas, it was determined that these challenges needed to be further explored. The following pages summarize the results from caregiver focus groups held around the state. Caregivers' own insights provide valuable information about these challenges and their effects.

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<sup>46</sup> <http://cfoweb.bdm.dhs.state.tx.us/ReferenceGuide/guides/FY09ReferenceGuide.pdf>

# Stakeholder focus groups: Assessing caregiver needs

In 2004, TDoA conducted a series of focus groups throughout the state involving caregivers, service providers, and other community stakeholders. The purpose was to obtain information on the needs of informal caregivers, the services available to them, their general level of access to those services, and any significant gaps in the system. Findings from these focus groups, unpublished until now, have been analyzed and grouped into five general areas of need:

1. The need for information
2. Employment
3. Caregiving in rural areas
4. Grandparents and relative caregivers, and
5. Coordination of services

What follows is a discussion of each area of need along with various recommendations that were identified and proposed by the participants of the focus groups.

## The need for information

*“People are just sitting out there wondering what they’re going to do with their grandmother. For children, I think it’s a little bit better because you have the school system. I’m going to go to my school principal. But for elderly people, if you take your older parents to the doctor’s office and ask, ‘I need some respite care,’ or ‘I need whatever,’ they’re going to go, ‘I don’t know.’”*

*“I have a college degree. I’m a well-known, intelligent person. I have no clue where to turn for help. It’s not necessarily whether you’re a PhD or a GED, it’s hard to know where to turn.”*

– quotes from stakeholders present at the Panhandle focus group

## Background

Most caregivers do not plan to be caregivers and, therefore, tend to be under-prepared for this new role in their lives. This results in some new caregivers not knowing where to turn to find information about available resources to obtain assistance. Consequently, this becomes one of the biggest barriers to informal caregivers having access to the services and supports they need. Further complicating this problem is the common failure of caregivers to “self-identify” – that is, describe themselves as caregivers for the particular purpose of obtaining assistance services. Without this self-identification, caregivers may not even be aware that they could qualify for

assistance, and providing them with services and supports in a timely fashion can be that much more difficult.

Though there are considerable resources committed to providing useful information, the results remain inconsistent. According to participants in the regional focus groups, there are three key problems they face in accessing information: finding information about an illness or medical condition with which the care receiver was diagnosed; finding resources in their community to assist with providing care; and finding information when it is needed.

## **Medical information**

When provided with a medical diagnosis for their loved ones, caregivers participating in the focus groups indicated often feeling they did not have enough information about a disease or condition, or its progression. They did not feel equipped to handle the patient's needs – physically, emotionally, or financially – and expressed a need for more information at a time when they could most benefit from having it. This was exacerbated for caregivers of individuals with Alzheimer's disease, who often require additional support from the medical community to help deal with the disease.

In the case of Alzheimer's patients, caregivers face high levels of stress and often require emotional support, counseling, and education programs about the disease as they strive to provide a safe and comfortable environment for the individual for whom they provide care. Physicians and other health professionals can be pivotal in helping provide critical information and resources. With adequate training, caregivers can learn how to control unwanted behaviors, improve communication, and keep the individual with Alzheimer's disease in the community. Research has shown that caregivers greatly benefit from training and support groups, and that participation in these groups typically allows caregivers to care for their loved one at home longer.<sup>47</sup>

A fairly recent development in the caregiver support arena is the use of evidence-based programs. In Central Texas, Scott & White Hospital has teamed up with the local AAA to administer the Reach II program, which includes a risk assessment and follow-up with information and resources tailored to meet the needs of the individual with Alzheimer's and those of family caregivers. More information on this innovative project can be found at the Rosalyn Carter Institute website.<sup>48</sup>

## **Awareness of community resources**

The need for general information about provider services in the community was cited by focus group participants as an ongoing issue for many caregivers. Many participants –

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47 Family Caregiver Alliance. (n.d.). *Fact Sheet: Alzheimer's Disease*. Retrieved July 14, 2009, from [www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=567](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=567)

48 [www.rosalyncarter.org/scottandwhite/](http://www.rosalyncarter.org/scottandwhite/)

particularly those dealing with caregiving issues for the first time – found navigating the system of caregiver services to be challenging. Caregivers listed word of mouth as their primary means of obtaining information on services, while some also reported that they relied heavily on AAAs for that information.

Despite the long-term presence of AAAs in communities throughout the state, many participants reported not being aware of them at all and were unsure of where to turn for assistance. The 2008 Aging Texas Well (ATW) Indicators Survey<sup>49</sup> found that 66 percent of older individuals in Texas had never heard of AAAs, the same result the survey found in 2004.<sup>50</sup> 2-1-1 (a statewide, comprehensive information and referral service), however, has become significantly more recognized in the community as a source of information. Twenty percent of those surveyed by the ATW Survey were aware of 2-1-1 in 2008, compared to only 8 percent in 2004.<sup>51</sup> In the focus groups, caregivers expressed the need for making better information available through outlets such as medical offices, targeted mailouts, and other information channels.

Information is currently available to caregivers from a variety of sources including:

- AAA information and referral system;
- 2-1-1 telephone system;
- Aging and Disability Resource Centers (discussed in detail later within Coordination of services section); and
- Websites such as Family Caregivers Online<sup>52</sup> – a collaboration of the Dallas County, Tarrant County, and North Central Texas AAAs to provide information for caregivers in one convenient location.

These agencies and programs represent some of the critical, “front door” resources that provide invaluable service to caregivers and consumers; however, more awareness of the availability of these services and supports is needed.

## **Timeliness of information**

Providing timely information services was also identified by the focus groups as an important factor in reaching caregivers. In general, potential caregivers do not pay

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49 DADS Aging Texas Well (ATW) Indicators survey is designed to assess how older Texans throughout the state are faring with respect to the ATW life areas, perceptions of their well-being, preparedness for the future, and awareness of available community resources. Findings are based on surveys of 1,100 age 60 plus individuals in a stratified random sample, with interviews in both Spanish and English.

50 Texas Department of Aging and Disability Services. (2009). *Aging Texas Well Indicators Survey, Overview Report, 2009*. Retrieved July 14, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/ATWIndicators2009.pdf](http://www.dads.state.tx.us/news_info/publications/studies/ATWIndicators2009.pdf)

51 Ibid.

52 [www.familycaregiversonline.com/](http://www.familycaregiversonline.com/)

attention to information about formal resources until a specific need arises, making it difficult to reach them. This also underscores the importance of identifying caregivers as caregivers – it is difficult to reach caregivers at the right time, especially when individuals may not yet identify themselves as caregivers.

One approach has been to collaborate with employers to reach out to working caregivers. Organizations such as AARP are encouraging employers to take a greater role in making caregiving information available to employees.<sup>53</sup> This increased awareness of caregiving issues could play a role in making information available in a timely fashion and in helping caregivers self-identify.

## **Stakeholder recommendations**

There is a clear need to make it as straightforward as possible for caregivers to access information about available services and supports. Caregivers participating in the focus groups often indicated being confused about not only what services are available to them, but also about the various types of services that would benefit them most as caregivers. The following is a list of recommendations that were identified by focus group participants, aimed at addressing caregivers' lack of information about available resources.

- Increase efforts to ensure that doctors and other medical professionals are informed about local support services and further ensure that they are making this information available and known to patients.
- Support efforts to ensure that caregivers receive information about patients' diagnoses that is accurate, clear, consistent, current, and easily accessible.
- Consider the use of an assessment tool that accounts for
  - the unique needs of both the caregiver and the care recipient,
  - identification of symptoms of and interventions for burnout, and
  - the need to distinguish between dementia vs. non-dementia caregiving.
- Develop a one-stop resource (e.g. website, call centers) that provides thorough and easy to understand information detailing the services available for consumers and caregivers.
- Raise awareness about the availability of services provided through AAAs.
- Support and encourage strategies at the local and regional level that will inform the public about caregiving. These should utilize and integrate the most common "critical pathways" to support, such as health care practitioners, pharmacists, discharge planners, and faith-based community organizations.

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53 U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. (2004). *When Employees Become Caregivers: A Manager's Workbook*. (Publication No. CMS-11035). Retrieved July 14, 2009, from [http://assets.aarp.org/www.aarp.org\\_/articles/careers/EmployeesBecomeCaregivers.pdf](http://assets.aarp.org/www.aarp.org_/articles/careers/EmployeesBecomeCaregivers.pdf)

- Increase awareness efforts directed at potential caregivers regarding the need to plan for future roles/needs as caregivers.
- Promote the establishment or enhancement of partnerships among health and social service providers to coordinate expanded support group activities.
- Ensure that outreach activities encourage those already providing care to loved ones to self-identify as caregivers.
- Examine the feasibility of public service announcements in areas where resources are underutilized, encouraging the use of available resources. This would require identification of underserved populations and the best means of communicating information to these markets.
- Consider less focus on generic information production and dissemination, as this may not always be cost effective. Promote locally and regionally specific information campaigns that address the particular caregiving issues of that community.
- Increase the availability of hands-on training for family caregivers. One example is the American Red Cross Family Caregiving Program.<sup>54</sup>

## Employment

*“What am I going to do when she’s at my house and I have to work? If I don’t work, we get in big trouble. I can’t afford to get a sitter to sit with her.”*

*“...but it still is difficult as far as sometimes dealing with the financial stuff and medical stuff. I do it during lunch hour, stay late. But I know there’s times when it bleeds over and it’s on the company time...and I feel guilty about that, but at the same time it can’t be helped.”*

*“They say, ‘Well, we understand if you’re dealing with little kids’...but they don’t understand the elderly issue, the time, what’s involved...and I think almost in some instances there’s a prejudice against if you have to deal with eldercare issues at the workplace...”*

– comments from stakeholders participating in the North Central Texas focus group

## Background

In 2004, the National Alliance for Caregiving conducted a survey in conjunction with the AARP, the results of which were subsequently published in a report titled *Caregiving in the U.S.* They reported that approximately 60 percent of caregivers currently work either full- or part-time while providing care, and that more than 60 percent of those working report that their caregiving responsibilities have affected their work.<sup>55</sup> Effects on work

<sup>54</sup> [www.redcrossstore.org/Shopper/Product.aspx?UniqueItemId=80](http://www.redcrossstore.org/Shopper/Product.aspx?UniqueItemId=80)

<sup>55</sup> National Alliance for Caregiving and AARP. (2004). *Caregiving in the U.S.* Retrieved July 14, 2009, from [www.caregiving.org/data/04finalreport.pdf](http://www.caregiving.org/data/04finalreport.pdf)

include making phone calls on behalf of the care receiver, using sick leave or vacation time, decreasing work hours, taking a leave of absence, moving from full- to part-time work, leaving employment or retiring early. Nationally, one study found that more than one-third of working caregivers had cut back on work hours or even quit work entirely.<sup>56</sup> For others, caregiver duties resulted in passing up career-enhancing opportunities such as training or promotions.<sup>57</sup>

Consequently, providing care affects earnings. Although no definitive number exists, studies have estimated that the average individual loss in total wealth over a lifetime was \$659,139 which includes lost wages, Social Security and retirement contributions (1999 dollars).<sup>58</sup> It has also been estimated that, nationwide, employee caregiving costs employers between \$17.1 and \$33.6 billion annually in lost productivity.<sup>59</sup>

## Supporting caregiver employment

Employers and employees who participated in the focus groups identified different, though interrelated, stresses of caregiving. Participating employers indicated a desire to be empathetic and supportive of caregivers but private sector employers have to ensure profitability and public sector employers have to be responsive to their statutory mandates. Employers who aspired to provide more tangible support to their employees expressed a need for better information and suggestions of creative ways to provide that support that did not interfere with work/production.

Employees indicated that their biggest challenge as working caregivers was balancing the need to remain productive at work while also fulfilling their caregiving responsibilities at home. They also stressed the importance of maintaining their job in order to provide financial security for the family and care recipient. Employees who wanted or needed to continue to work wanted better information from their employers and more flexible hours to allow them to work and provide care.

Caregivers participating in the focus groups identified “flex-time” as the most important support that employers can offer. Flex-time allows caregivers the opportunity to adjust their schedules in order to meet their responsibilities as both

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56 National Alliance for Caregiving & Evercare. (2007). *The Evercare Study of Family Caregivers – What They Spend, What They Sacrifice*. July 14, 2009, from [www.caregiving.org/data/Evercare\\_NAC\\_CaregiverCostStudyFINAL20111907.pdf](http://www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf)

57 Coleman, B. and Pandya, S. (2002). *Fact Sheet-Family Caregiving and Long-Term Care*. AARP Public Policy Institute, Washington, D.C. (Pub. ID FS91). Retrieved July 14, 2009, from [www.aarp.org/research/housing-mobility/caregiving/aresearch-import-779-FS91.html](http://www.aarp.org/research/housing-mobility/caregiving/aresearch-import-779-FS91.html)

58 National Alliance for Caregiving and the National Center on Women and Aging at Brandeis University. (1999). *The MetLife Juggling Act Study. Balancing Caregiving with Work and the Costs Involved*. Retrieved July 15, 2009, from [www.caregiving.org/data/jugglingstudy.pdf](http://www.caregiving.org/data/jugglingstudy.pdf)

59 National Alliance for Caregiving and the MetLife Mature Market Institute. (2006). *The Metlife Caregiving Costs Study: Productivity Losses to U.S. Businesses*. Retrieved July 15, 2009, from [www.metlife.com/assets/cao/mmi/publications/studies/MMI-Studies-Caregiver-Cost-Study.pdf](http://www.metlife.com/assets/cao/mmi/publications/studies/MMI-Studies-Caregiver-Cost-Study.pdf)

caregivers and employees. To address this issue, many states are increasing efforts to encourage and provide incentives for employers to find creative approaches that ensure that caregivers (and company managers) have this option available to them.

## Stakeholder recommendations

Caregivers employed outside of the home face significant challenges, as do their employers. Focus group participants and other aging stakeholders recommend:

- Considering public policy that provides financial and other types of incentives to employers who offer flex-time, paid leave, and/or other benefits and support to employee caregivers.
- Coordinating with large employers in major metropolitan areas to bring together businesses for roundtable discussions on caregiver issues.
- Supporting a statewide survey of state agencies and state employees to evaluate the effect of caregiving on state employees and the state workplace.
- Raising awareness of and encouraging the provision and use of eldercare support services such as education and training or consultation on life/work balance through Employee Assistance Programs. Programs such as the American Business Collaboration for Quality Dependent Care<sup>60</sup> can be useful resources in helping corporations provide these supports.

## Caregiving in rural areas

*“If you take away their driving, how are they going to receive services that they need, like getting to the doctor? We have fairly good services within the metro area here, but out in the rural area, (it’s difficult) trying to get people transported in to get health care or the things that we sort of take for granted...”*

*“I see that there’s not a lot of services out there for the elderly for transportation, things that will help relieve the sons and daughters because that’s a big problem. Transportation’s huge. They can’t drive anymore.”*

– statements from stakeholders attending several rural focus groups

## Background

Access to quality health services was identified as one the leading concerns in one survey of aging stakeholders and state and local rural health experts.<sup>61</sup> Most rural areas

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60 [www.abcdependentcare.com/docs/tools.shtml](http://www.abcdependentcare.com/docs/tools.shtml)

61 Hutchison, L., Hawes, C., & Williams, L. (2005). Access to Quality Health Services in Rural Areas – Long-term Care. In Gamm, L. and Hutchison, L. (Eds.), *Rural Healthy People 2010: A companion document to Healthy People 2010*. Volume 3. College Station, TX: The Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Research Center. Retrieved July 15, 2009, from [www.srph.tamhsc.edu/centers/rhp2010](http://www.srph.tamhsc.edu/centers/rhp2010).

face a lack of health services, lack of infrastructure, high poverty levels, and geographic isolation. A lack of available and accessible support services can leave caregivers with limited options for getting the assistance they need.

The specific issue of family caregiver support may be more pressing in rural areas, where there is a higher proportion of the elderly. According to the U.S. Census Bureau, in 2005, an estimated 3.2 million individuals (nearly 15 percent of the total population) in Texas were 60 years or older.<sup>62</sup> The concentration of elderly Texans is greatest – approximately 2.4 million – in what are considered to be rural counties.<sup>63</sup> Focus group participants in rural areas reported having less access to skilled nursing and other long-term care services compared to their urban and suburban counterparts. Without these formal services available, caregivers and care recipients in rural areas rely even more on family and friends for assistance.

## **Workforce shortage**

The shortage of health care workers is one of the leading challenges of providing support to informal caregivers in rural areas. Service providers in rural areas face distinct challenges in recruitment and retention of workers due to a less educated workforce, limited continuing education opportunities, lower salaries, lack of prestige and high stress levels associated with the job.

According to the Family Caregiver Alliance's State of the States in Family Caregiver Support, more than 35 percent of state program administrators face a shortage of qualified service providers or direct care workers.<sup>64</sup> This workforce shortage results in considerable unfilled need and is often cited among service providers as one of the main challenges in providing services and support in rural areas. Without these professional supports, informal caregivers can find themselves with little or no assistance as they care for their loved one themselves.

## **Transportation**

Lack of adequate transportation is also a major barrier for informal caregiving in rural parts of Texas. Geographic isolation results in family caregivers having to travel greater distances just to reach those they care for, in addition to transporting care recipients to required services such as medical care. More than 20 percent of respondents who self-identified as caregivers to the 2008 Aging Texas Well Indicators Study reported

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62 Texas Department of Aging and Disability Services. (2007). *Texas State Plan on Aging, 2008-2010*. Retrieved July 15, 2009, from [www.dads.state.tx.us/news\\_info/publications/planning/stateplanonaging/2008-2010/stateplan2008-2010.pdf](http://www.dads.state.tx.us/news_info/publications/planning/stateplanonaging/2008-2010/stateplan2008-2010.pdf)

63 Ibid.

64 Feinberg, L.F, Newman, S.L., Gray, L. & Kolb, K.N. (2004, November) *The State of the States in Family Caregiver Support: A 50-state study*. Family Caregiver Alliance, San Francisco, CA.

that they travel more than 50 miles to provide care.<sup>65</sup> Older Texans in rural areas also experience poverty in greater numbers than their urban counterparts, and may be unable to afford reliable transportation or keep pace with fluctuating fuel costs.

High transportation costs also create a specific challenge for in-home service providers and their employees in rural areas of the state. Low or non-existent mileage reimbursement drastically affects a direct care worker's ability to cover the cost of fuel and vehicle maintenance, particularly when they are required to drive long distances to reach the individual for whom they provide services. This situation can further increase the workforce shortage problem described above, resulting in an even greater need for informal care.

## **Access to services**

The challenge of finding and receiving community support is a particular concern in rural areas where limitations on providers, access to services, information, and ongoing support make it harder for individuals to care for loved ones in their homes. Institutional admission rates for rural elders are typically higher than in urban communities.<sup>66</sup> Caregivers in rural areas often do not access services because they are unaware of existing programs, do not know they are eligible, do not accept services until there is a crisis, and find services too geographically distant.<sup>67</sup> These concerns were echoed by participants in the focus groups.

One effort to address these issues occurred in the West Texas area, where six AAAs collaborated with the Texas Tech University Health Sciences Center to develop West Texas Cares.<sup>68</sup> This initiative focused specifically on caregiver outreach and education to meet the needs of rural family caregivers in West Texas. Additionally, the expansion of the ADRC program to five new sites (and a sixth sometime in 2010), including several rural areas, should address some of these challenges.

## **Stakeholder recommendations**

Caregivers in rural areas face a unique set of challenges, from population distribution to access to formal supports and a shortage in the workforce providing those formal services. The following recommendations were offered by stakeholders attending the focus groups to address the specific problems that caregivers encounter in rural parts of Texas:

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65 Texas Department of Aging and Disability Services. (2009). *Aging Texas Well Indicators Survey, Overview Report, 2009*. Retrieved July 15, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/ATWIndicators2009.pdf](http://www.dads.state.tx.us/news_info/publications/studies/ATWIndicators2009.pdf)

66 Texas Department of Aging and Disability Services. (updated November 12, 2008). *Support for Caregivers*. Retrieved July 15, 2009, from [www.agingtexaswell.org/caregiving/caregiver\\_support.html](http://www.agingtexaswell.org/caregiving/caregiver_support.html)

67 Ibid.

68 [www.westtexascares.com/default.asp](http://www.westtexascares.com/default.asp)

- Examine the feasibility of higher mileage reimbursement for direct service workers to provide greater incentive to serve rural or remote areas of the state.
- Enhance ongoing efforts to increase the number of skilled health care workers in rural areas, including coordinating with local community colleges to offer educational and training opportunities.
- Develop outreach efforts to caregivers that consider that the need for information may be greater and/or different in rural areas than in urban and suburban parts of the state. These efforts should both address and be informed by these differences.
- Consider efforts to ensure that reimbursement rates for long-term care services keep pace with the rising cost of living and doing business in rural areas. Adequate funding and reimbursement rates are critical to address the shortages of direct care workers in rural areas.
- Consider expansion of consumer directed service options to include the use of vouchers for transportation services.

## Grandparents and relative caregivers

*“We’re very limited in what we can really do to help them...because of the income guidelines and the legal barriers and that sort of thing. We see a lot more grandparents involved in kid’s lives, but it’s a lot harder to help them because of the legal barriers.”*

*“We run into something else with these grandparents, and that is that many times the children that they’re taking care of have behaviors that are way beyond their scope of coping. A lot of defiance issues, and there doesn’t seem to be anything in the community that helps them with those children.”*

– comments from service provider participants in various focus groups

## Background

Adults over 60 are increasingly becoming primary caregivers to grandchildren or other relative children. The 2000 U.S. Census reported that more than 5.5 million grandparents co-resided with at least one grandchild, and that 42 percent of those (nearly 2.5 million) considered themselves to be “currently responsible for most of the basic needs” of these grandchildren.<sup>69</sup> In Texas, almost 450,000 children (7.6 percent of children in the state) live in grandparent-headed households.<sup>70</sup> There are more than 150,000 children living in households headed by other (non-parent) relatives (2.6

69 Simmons, T. & Dye, J.L. (2003). *Grandparents Living With Grandchildren: 2000*. Washington, D.C.: U.S. Bureau of the Census, Population Division.

70 AARP Grandparent Information Center. (2007). *Texas: A State Fact Sheet for Grandparents and Other Relatives Raising Children*. Retrieved July 15, 2009, from [www.grandfactsheets.org/doc/Texas07-final.pdf](http://www.grandfactsheets.org/doc/Texas07-final.pdf).

percent of all children in the state).<sup>71</sup> Seven percent of respondents to the Aging Texas Well Indicators Study reported that they are the primary caregiver for children under age 18 and almost half (44 percent) have been providing care for five years or less. More than half of those providing care to grandchildren have no legal designation or custody of the child, other than relative status.<sup>72</sup>

Many of these relative caregivers, also referred to as “kinship caregivers,” often become surrogate parents as a result of divorce, crime, child abuse and neglect, the rise in single-parent households, illness, or substance abuse among the middle generation. Grandparents face issues related to school systems, finances, health insurance, managing difficult care, disability, and often need assistance in legal matters involving custody, guardianship, and conservatorship. Grandparents and other kinship caregivers often lack information about available benefits and support services needed to fulfill their caregiving role. Many are reluctant to seek services for fear of bringing unwanted official attention to their non-traditional and often legally unrecognized family situations.

To address these specific needs, community-based organizations such as AAAs provide resources, support groups, and services that are tailored to the unique needs of grandparents and relative caregivers. However, the Aging Texas Well Indicators Study reports that 73 percent of grandparent caregivers do not use support services, and 63 percent are unaware of the resources available to them through AAAs.<sup>73</sup>

## Recognizing kincare

With an estimated more than 600,000 children in Texas during any one year who (for at least some part of that year) are cared for by a relative who is not their parent,<sup>74</sup> the importance of recognizing kincare and the specific challenges these relative caregivers face is a growing need. Most caregivers step into these roles unexpectedly and are not prepared for the financial, emotional, or logistical challenges of providing care. Grandparent caregivers often spend down their retirement savings and are forced to give up their jobs to raise grandchildren. Nearly 20 percent of the children being cared for by grandparents are living in poverty, with higher incidence of physical, mental and learning disabilities, and a third have no health insurance.<sup>75</sup>

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71 Ibid.

72 Texas Department of Aging and Disability Services. (2009). *Aging Texas Well Indicators Survey, Overview Report, 2009*. Retrieved July 15, 2009, from [www.dads.state.tx.us/news\\_info/publications/studies/ATWIndicators2009.pdf](http://www.dads.state.tx.us/news_info/publications/studies/ATWIndicators2009.pdf)

73 Ibid.

74 Texas Kincare Taskforce (n.d.). *Texas Kincare Primer*. Retrieved August 7, 2009, from <http://fcs.tamu.edu/families/aging/grg/primer-english.pdf>

75 AARP International. (2008, April). *Who Is Raising the World's Children? Grandparent Caregivers: Economic, Social and Legal Implications*. (Proceedings of a joint panel discussion, Washington, D.C.) Retrieved July 15, 2009, from [www.aarpinternational.org/resourcelibrary/resourcelibrary\\_show.htm?doc\\_id=676636](http://www.aarpinternational.org/resourcelibrary/resourcelibrary_show.htm?doc_id=676636)

Some measures have been taken to recognize the role of grandparents raising grandchildren. In 2006, the definition of “grandparent or relative caregiver” in the Older Americans Act was amended to include “those 55 years of age or older caring for a child to whom they are related by blood, marriage or adoption.”<sup>76</sup> Grandparents or relative caregivers caring for children with severe disabilities were also included as a “priority population” for NFCSP services. Federal law allows up to 10 percent of NFCSP funding to be used to provide support services to grandparents or older relatives who are raising relatives’ children.<sup>77</sup>

The Texas Kinicare Task Force, a collaboration of state and local partners and kinship caregivers, works to address legislative, educational and program development for kinship caregivers throughout the state. The task force is currently working on a power of attorney for kinship caregivers, designed to help deal with legal issues that are often troublesome for grandparents or relatives raising children who are not their own. The task force, with the help of Texas A&M University, also supports the website Grandparents Raising Grandkids,<sup>78</sup> which provides caregivers with information about legal services, support groups, and other helpful resources.

## **Outreach**

Though there are many programs to help support kinship caregivers, making caregivers aware of them remains a challenge. In Texas, Child Protective Services (CPS), a division of the Texas Department of Family and Protective Services offers a range of information through its Kinship Program. With the support of the Casey Foundation, the Kinship Program helps match caregivers with community supports and services, and assists with tasks such as navigating the court system, among others.

For families that are not a part of a formal system such as CPS, outreach can be an even greater challenge. Many AAAs, such as the one serving Bexar County, have taken steps to reach these caregivers in community settings, such as public schools. Through these local and familiar settings, the AAA is able to better identify kinship caregivers and provide information on available supports and services. The Bexar County and Texoma AAAs both have programs specifically designed to address the needs of kinship caregivers.

## **Stakeholder recommendations**

Raising grandchildren and/or other relative children poses a specific set of complex obstacles to these kinship caregivers. Focus group participants made the following

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76 Older Americans Act of 1965, 42 U.S.C. § 3030s. Retrieved July 15, 2009, from [www.gpoaccess.gov/USCODE/index.html](http://www.gpoaccess.gov/USCODE/index.html)

77 Beltran, Ana. (n.d.). *National Family Caregivers Support Program: Narrative Analysis*. Grandfamilies State Law and Policy Resource Center. Retrieved July 15, 2009, from <http://grandfamilies.org/index.cfm?page=topics&topicid=33>

78 <http://grandparentsraisinggrandkids.tamu.edu>

suggestions to reduce the negative effects of these obstacles and provide support to this substantial group of informal caregivers:

- Consider the continued expansion of the Temporary Assistance for Needy Families (TANF) program to support grandparent caregivers.
  - Focus group respondents reported a need to expand beyond giving only a one-time cash payment of \$1,000, and a need to expand the definition of caregiver.
  - Increase awareness of TANF to ensure those who are eligible apply.
- Support the expansion of rights for kinship caregivers in areas such as medical consent, standby guardianship, and custody proceedings.
- Promote the use of NFCSP funding designated for serving grandparent caregivers to encourage new and improved connections between the aging network and providers who specialize in serving these unique caregivers.
- Examine the feasibility of programs such as the one in Washington, D.C. that pays grandparents – rather than foster care – to provide care to the grandchildren.
- Consider expansion of innovative programs, policies, and practices that allow AAAs to assist grandparents and relative caregivers such as:
  - Bexar AAA partnerships with school districts to identify and provide information and resources to kinship caregivers,
  - The San Angelo Grandparents Raising Grandchildren conference, and partnerships with Headstart and local school districts, and
  - AAAs use of legal assistance funds to provide support to grandparents.

## Coordination of services

*“... You feel like a mule sometimes, like everything is on your back and just (doing) one thing (after) another is so hard...In a period of time of about five years, I honestly thought I was going to go insane, because all I was doing was this, just running from one spot to another. Doing this is tough.”*

*“I think one of the most clear examples...is when you’re on an airplane and they tell you, if the masks drop down, put it on your face first and then assist the person who’s with you...we’re so busy getting the mask on the other guy that most of us are suffocating under the pressure of what’s going on because we either don’t have time, can’t find time, don’t have the support, don’t know about the support.”*

– statements from caregivers attending the Capital Area Council of Government focus group

## **Background**

Caregivers and providers participating in the focus group sessions indicated that they often found it difficult to obtain integrated information and to coordinate services for the care receiver. Many focus group participants indicated that they were often required to complete multiple forms and provide the same information for several agencies because agencies do not share information. They also reported that:

- Many employers and physicians were not familiar with community resources,
- There was often a lack of follow-up with referrals made by one agency to another, and
- The absence of a central clearinghouse of information on formal and informal community services is a barrier to effective service coordination.

In response to many of these issues, DADS is taking steps to help identify ways to improve coordination of services at the local level to ensure greater accessibility to DADS programs and other services and supports.

## **Aging and Disability Resource Centers (ADRCs)**

In December 2005, working closely with community stakeholders, DADS began an initiative to design a new integrated and comprehensive service delivery system for Texans who are aging and/or are in need of long-term care disability supports and services. As part of this project, DADS staff applied for and received a three-year grant to pilot up to three ADRCs in Texas through a grant jointly funded by the AoA and the Centers for Medicare and Medicaid Services. The purpose of ADRCs is to organize, simplify and ensure access to aging and disability services for older individuals, individuals with disabilities and those with mental retardation, and the caregivers who care for them.

ADRCs provide information, referral and counseling for public and private pay individuals, community awareness of public and private long-term care options, help for individuals in assessing their eligibility for benefits, case management, coordination with Medicaid eligibility determination, and individual plans for long-term care needs. ADRCs can also provide short-term service coordination, working with individuals to develop a person-centered plan and to assist in the selection of services and supports and providers. DADS began with three ADRC pilot sites – one serving Bexar County, one located in Milam County that serves a seven-county area, and one serving Tarrant County. The project expanded in 2009 to include sites in five additional areas of the state; one each in Houston/Harris County, Dallas County, Lubbock County, East Texas (serving six counties), and North/Central Texas (serving four counties). Also in September 2009, DADS received from AoA a new grant to expand the ADRC program. Funding will provide for the establishment of a new ADRC site (to be determined in 2010), as well as develop a five-year plan to make ADRCs statewide in Texas.

## **Community roundtables**

Beginning in 2007, staff from DADS' Access and Intake division worked with AAAs, mental retardation authorities, and regional and local services staff to plan and convene a series of community roundtables in 16 locations throughout the state. The goal of these roundtables was to determine what can be done at the state and local level to integrate these agencies' services (and access processes) in a way that makes the most sense to consumers. The series continued throughout 2008 and was completed in the spring of 2009. The roundtables have assisted DADS in finding ways to coordinate services for shared stakeholders (including caregivers) between the participating agencies.

Examples of local commitments made by agencies at several of the roundtables included memoranda of agreement, which streamlined referral protocols among the DADS local partners, including:

- The use of electronically shared referral forms;
- Formal interagency training plans;
- Integrated marketing and outreach activities; and
- Employing the use of system navigators (similar to those in ADRCs) in each agency to assist consumers make their way across the DADS system of services and programs.

These initiatives should help increase consumer awareness of available services, and help Texas' state and local services become more accessible.

## **Stakeholder recommendations**

Similarly to the identified need for information, stakeholders participating in the focus groups recognized the importance of coordinating needed services for care receivers and caregivers. Experiences with repetitive application processes and lack of communication between service providers led participants to put forward the following recommendations:

- Minimize paperwork and other administrative barriers to obtaining services for caregivers.
- Encourage service providers to provide a full continuum of services, and explore incentives that might help facilitate this.
- Integrate existing services across programs and enhance coordination of long-term care activities.
- Encourage formal services as a support to informal services, specifically communicating the message that formal services do not have to be an "all or nothing" proposition, and ensure that formal services are compatible with and complementary to informal services.

- Continue to work on the “one stop/no wrong door” approach to service delivery: ensure that the referral system among agencies is responsive, reliable, and accurate; be creative in getting information about service needs and resources to the community by not simply targeting the obvious places; and ensure that caregiving coordination is a priority as part of system redesign efforts.
- Encourage a caregiver resource center as a part of the ADRC grants implementation.
- Consider creating a state-level caregiver advisory group that meets quarterly and is comprised of representatives from AAAs and personnel from the caregiver resource centers.
- Consider establishing a single point of contact at the state level to coordinate state caregiver support efforts and to develop model communication pieces and other materials to enhance training for caregivers.
- Explore ways to ensure program affordability for those who do not qualify for Medicaid and/or waiver programs. Private pay rates for in-home care are too high for many caregivers to pay on their own, creating a barrier to seeking and receiving assistance.

## Conclusion

Informal or family caregiving remains one of the most essential parts of Texas' system of long-term care. The continued support of these caregivers by the state and federal governments is a charge of vital importance. Providing services and supports to this population promotes families, independence, aging well, and delays or removes the need for individuals to utilize costly institutional care.

This report on family caregiving in Texas has brought together the voices of caregivers and other stakeholders from throughout the state. Their concerns and insights, born of direct experience caring for some of Texas' most vulnerable residents, speak volumes not only about the daily challenges they face, but of their hopefulness and continued desire to care for their loved ones at home. The recommendations from the stakeholder focus groups both reinforce and are reinforced by statements and publications from state and national government agencies and experts alike, as evidenced throughout the report.

In January 2009, the staff of the Legislative Budget Board (LBB) submitted its report titled *Texas State Government Effectiveness and Efficiency: Selected Issues and Recommendations* to the 81st Texas Legislature. One of the analyses within the Health and Human Services functional area, titled "Strengthen the Delivery of Informal Caregiver Support Services," clearly echoed stakeholder recommendations from the statewide focus groups. Specifically, the LBB's report recommended coordination of public awareness efforts by AAAs regarding the caregiver role and available services, standardizing and including caregiver questions in assessment tools and processes, and analysis of statewide caregiver data collected at assessment to inform current and future system development.<sup>79</sup>

Informal or family caregivers, whether a grandparent caring for a grandchild or someone caring for an older family member or friend, have identifiable needs for services and support. When these needs are met, the caregiver is able to continue to provide informal care for a longer period of time. The longer that care is provided by informal caregivers, the less effect on public funds and public programs for formal care through both community-based and institutionally-based settings. Stakeholders and experts agree that budgetary constraints, along with the rising cost of providing formal care and services to individuals, could be addressed by further recognition of the value of informal caregivers and the need for supportive services so they can and will continue to provide quality care for their loved ones in the community.

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<sup>79</sup> State of Texas Legislative Budget Board Staff. (2009). *Texas State Government Effectiveness and Efficiency: Selected Issues and Recommendations, January, 2009*. Retrieved July 15, 2009, from [www.lbb.state.tx.us/Performance%20Reporting/TX\\_Govt\\_Effective\\_Efficiency\\_Report\\_81th\\_0109.pdf](http://www.lbb.state.tx.us/Performance%20Reporting/TX_Govt_Effective_Efficiency_Report_81th_0109.pdf)

# Appendix

Note: All services available through the OAA are not provided by each AAA in Texas. Services provided through AAAs are not entitlement services and are intended to be provided only on a short-term basis or as gap filling services for individuals and caregivers. AAAs, through the provision of care coordination and caregiver support coordination, make referrals to other agencies and assist in many other ways than are identified on this list.

- Older Americans Act, Title III-E National Family Caregiver Support Program Services available through AAAs.
- Caregiver information services: assistance in obtaining services in the community (e.g., resource libraries, information centers).
- Caregiver support coordination: assistance with planning, arranging, and coordinating needed services for the caregiver.
- Legal assistance/benefits counseling: provides information on and assistance with benefits entitlements and/or attorneys' help with legal matters.
- Caregiver education and training: assists caregivers in conducting activities related to caregiving, making decisions and in solving problems (e.g., legal, medical, financial) and may include caregiver support groups, which provide social interaction and emotional support to informal family caregivers.
- Respite services: assistance with temporary relief for the caregiver that can range from a few hours to several weeks and can be provided in the home by a vendor agency or through a respite voucher program, in a licensed residential facility such as an adult day care or assisted living facility, or in a non-licensed, non-residential setting, such as a community senior center.
- Homemaker services: assistance with housekeeping/home management tasks such as meal preparation and shopping.
- Personal assistance services: provides home care assistants to help with bathing, dressing, toileting, housekeeping, domestic chores, and other daily activities.
- Transportation services: provides transportation to and from senior centers, doctors' appointments, shopping and other essential destinations; and assisted transportation services that provide assistance to individuals who have difficulties using regular vehicular transportation.
- Home-delivered meals: provides meals delivered to the individual to support healthy, independent living through proper nutrition.
- Health maintenance services: including, but are not limited to durable medical equipment and assistive devices, prescription drug assistance, physical and speech therapy, oral health, and optical services.

- Chore maintenance: performs household chores such as heavy cleaning, yard and walk maintenance, and moving heavy furniture.
- Emergency response: links the frail older person with emergency medical services using an automatic monitoring system that is monitored by a vendor agency.
- Escort services: provides a person to accompany and assist the individual with obtaining services in the community.
- Hospice services: provides a home or a residential setting for services.
- Mental health services: provides services to support and improve the emotional well-being of the individual.
- Physical fitness and recreation: provides activities to sustain and/or improve physical and mental health. (Does not include physical therapy services.)
- Residential repair: provides repairs or modifications to the individual's home.
- Shopping services: assistance with shopping for food, clothing, medical supplies, and household items.
- Telephone reassurance and visiting: provides daily or routine phone calls or visits to the individual's home providing companionship and reducing individual isolation.



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