



TEXAS
Health and Human
Services

Aging Texas Well

Policy Brief

Economic Security for Informal Caregivers

In Texas, an estimated 3.4 million people provide unpaid care (informal caregiving) for at least one older adult or person with a disability.¹ An informal caregiver, also referred to as an unpaid or family caregiver, is a person who provides care to someone they have a personal relationship with.² Informal caregivers help with a variety of activities and tasks, such as bathing, dressing, paying bills, administering medication, etc. It is estimated that each year they provide 2.9 billion hours of uncompensated care with an economic value of \$35 billion.³



Without informal caregivers, this substantial responsibility of caring for community members falls onto the health care, social services and long-term care systems. These systems are largely unequipped to be the sole support systems, especially when considering the preference for aging in place. A study by AARP found that 77% of people age 50 and older wish to continue living in their home as they age.⁴ Informal caregivers not only provide huge economic value, they allow older adults the choice to remain at home and to be cared for as they want.

Caregiving can be a wonderful and meaningful experience but can also bring financial challenges. About 51% of caregivers report that the act of caregiving provides them with a sense of purpose and meaning in their life, and caregivers providing higher levels of care are even more likely to report having this sense of purpose.⁵ It is critical that informal caregivers have economic security so they can effectively provide this vital care for their loved ones without compromising their own well-being.

HIGH COST OF CAREGIVING

About 75% of informal caregivers regularly spend their own money on caregiving expenses (e.g., home modifications, medical treatments, medical equipment, respite care, recreation), and 67% of caregivers report making at least one personal sacrifice (e.g., less vacationing, reduced grocery spending, medications, health care for themselves) due to the costs of caregiving.⁶

EMPLOYED WHILE CAREGIVING

About 60% of informal caregivers are employed outside of their caregiving responsibilities.⁷ Caregiving while working often comes with more challenges. Evidence shows that informal caregivers who work fulltime have poorer financial

well-being than full-time, working non-caregiver peers. The disparities are even greater for caregivers under age 45, which may be explained by being less established in their careers and having less savings.⁸

The financial challenges that working informal caregivers face may be what pushes them into the role of caregiving in the first place and at the same time, may be further strained because of caregiving. People with lower incomes have less resources to pay for outside care, leading them to take on caregiving responsibilities.⁹ When taking on these responsibilities, the same caregivers often incur the additional financial costs referenced previously.

Other challenges include impacts to employment. Depending on the care recipient's needs, caregiving can be time-consuming and stressful, making it hard to be attentive to one's job. Some caregivers work less hours to provide care, while others take on more hours to afford caregiving expenses. Some caregivers need to take a leave of absence to attend to caregiving duties, which can put them behind in their career and leave them with less money.¹⁰ When thinking about how to support informal caregivers who are working, these potential challenges should be considered.

The U.S. Family and Medical Leave Act (FMLA) provides limited protections to family caregivers. FMLA applies to employees who work for a private company with at least 50 employees or a public agency of any size. FMLA covers employees taking unpaid leave for up to 12 weeks to care for a spouse, child or parent.¹¹ About one quarter of Texas' informal caregivers are caring for a person age 60 and older who is a grandparent, parent-in-law, sibling, friend or neighbor. These caregivers do not fit in to one of these relational categories.¹²



Greater workplace benefits can be provided to support working informal caregivers by expanding leave policies. The definition of who is considered "family" can be expanded to include extended family members and family of choice. Employers can also provide paid sick leave and consider caregiving-related tasks as valid uses of earned sick leave. Caregivers with sick or family leave are less likely to quit their jobs than those without these benefits, reducing staff turnover.¹³ Enhanced workplace leave policies ultimately benefit both the working informal caregiver and the employer.

ECONOMIC SUPPORT FOR FAMILY CAREGIVING

Some limited financial supports currently exist for informal caregivers in Texas. For people who meet the eligibility requirements, there are social service programs that pay for personal assistance and other services. At the federal level, tax deductions for medical expenses are also available.

Three programs that pay eligible informal caregivers to help with personal care tasks are the STAR+PLUS Home and Community Based Services program, the Community First Choice program and the Community Care Service program. More services may be provided through these programs that may help alleviate

potential financial expenses, such as respite care, meal services and day activities. There are strict eligibility requirements for these programs, including very low income and assets, that care recipients or caregivers must meet to access funding. Spouses, and in some instances, other people living in the home, do not qualify to be paid through these programs.^{14,15,16}

The National Family Caregiver Support Program provides funding for Area Agencies on Aging and Aging Disability Resource Centers to provide services that can benefit informal caregivers. As funding allows, they provide limited assistance with respite care, transportation, home modifications and medical equipment.¹⁷

A different form of financial assistance for caregivers is a tax deduction for medical expenses paid for on behalf of the person receiving care.¹⁸ As referenced previously, 75% of informal caregivers pay for caregiving expenses with their own funds, and 17% of caregiving expenses are spent on medical costs.¹⁹ If the person receiving care meets certain criteria, the informal caregiver may deduct medical expenses they paid for.²⁰

In addition to making sure economic supports for informal caregivers are available, it is important to make sure caregivers are aware of existing support services. The National Academy for State Health Policy released a roadmap for states that focuses broadly on bringing awareness to various available supports, including financial support for family caregivers. This outreach is needed because not all caregivers identify themselves as a caregiver, much less know about the support available to them.²¹ The roadmap presents four promising practices:



1. Carry out a public outreach campaign to educate people about caregiving supports and services.
2. Incorporate outreach strategies into state regulation and policy.
3. Incorporate family caregiver outreach in state planning.
4. Start a family caregiver taskforce.

The Texas Health and Human Services Commission (HHSC) is in the planning phase of the first practice, which is to carry out a public outreach campaign for informal caregivers. HHSC has also engaged in the third practice, which is incorporating family caregiver outreach in the Aging Texas Well Strategic Plan.²² The second and fourth practices can be used to further enhance awareness of services for informal caregivers. Given the importance and challenges of financial security for informal caregivers, it would be helpful to make sure to include a focus on bringing awareness to financial support in these outreach efforts.

CONCLUSION

Informal caregivers are vital to the well-being of older Texans. They help their loved ones to continue to live in their homes and communities as they age. Many caregivers find fulfillment in their role as a caregiver, but caregiving can be financially burdensome, and caregiving while being employed has more

challenges. Supportive family leave policies and other workplace benefits are helpful for working caregivers and can reduce staff turnover.

A few programs are available that provide financial compensation to some informal caregivers with specific eligibility requirements. A tax deduction is also available in some circumstances to family caregivers paying for medical expenses. Furthermore, increasing public awareness of available financial and other supports for caregivers can be helpful. Supporting the financial well-being of informal caregivers is important to be able to provide exceptional care to older Texans.

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