

Services and Supports for Unpaid Caregivers of People Living with Alzheimer's Disease and Related Dementias (ADRD)

A Statewide Needs Assessment



TEXAS A&M HEALTH
Center for Community
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EXECUTIVE SUMMARY

The Texas A&M School of Public Health was contracted by the Texas Department of State Health Services (DSHS) to perform a statewide needs assessment of services and supports for unpaid caregivers of people living with Alzheimer's Disease and related dementias (ADRD). The needs assessment aimed to better understand the availability, accessibility, and use of services for ADRD caregivers in Texas. It also sought to identify the unmet needs and barriers to service access and utilization from the perspective of unpaid caregivers and the organizations that serve and support them.

This needs assessment included two statewide surveys and a series of four virtual Community Discussion Groups (CDG). The surveys collected complementary information from two audiences: (1) unpaid ADRD caregivers and (2) organizations serving unpaid ADRD caregivers. The CDG gathered more in-depth qualitative data from organizations serving regions with high ADRD burden (i.e., East Texas, rural communities, Hispanic/Latino communities) about the needs of unpaid ADRD caregivers, service adequacy and deficits, barriers to service utilization, and needs to improve service delivery.

About 580 caregivers and 50 organizations across urban and rural regions of Texas completed the surveys. Twenty-nine individuals across four regions participated in the virtual CDG.

Most of the unpaid caregiver survey respondents resided in metropolitan areas (83.3%). Caregivers most often reported needing but not using services such as caregiving technologies, dementia research updates, community resources, health and wellness programs, and respite care. Substantial numbers of caregivers reported that services and resources such as technology, transportation, and care planning were not available in their area. Between 40% and 49% of caregivers reported that most ADRD-related services were difficult to access in their areas, which was more pronounced among caregivers living in rural communities.

Admittedly, many caregivers self-reported having low awareness about community resources. However, they also perceived that their communities did not have enough community resources to support caregivers and their care recipients. Most caregivers reported that they needed help learning how to care for their care recipient and that they lacked money to provide the best care. Caregivers reported not knowing who to call for caregiving needs and being unable to get appointments as non-financial barriers to services. In addition, a substantial number of caregivers reported that caregiving negatively affected their mental health, social life, and sleep, highlighting the toll of caregiving on personal well-being.

Organizations confirmed many of the concerns and barriers raised by caregivers, but they also highlighted systemic challenges that may prevent caregivers from being aware of available services. Compared to caregivers, larger proportions of organizations reported that caregiving services were available and easy to access. While most organizations provide community resources, information, care planning, health and wellness programs, end-of-life planning, and

respite care, fewer organizations offered supports such as financial and legal planning, transportation services, or technologies for caregiving. Organizations pointed to structural barriers to service accessibility, which include difficulty navigating complex care systems, long waitlists, shortages of trained dementia specialists, poor internet access, and geographic distance. They emphasized that rural, low-income, older, disabled, and Hispanic/Latino caregivers are disproportionately affected by these barriers.

To complement the surveys, CDG revealed six recurring themes. Caregivers often prioritize their care recipient's needs above their own, leading to burnout and neglect of self-care. Many caregivers lack awareness about available services or face logistical challenges to access needed services. CDG participants stressed the importance of early intervention at the time of diagnosis, culturally appropriate outreach, and better support for caregivers who struggle with technology. CDG participants identified workforce shortages as a major obstacle, particularly in rural regions, which underscores the need for strategies to attract and retain dementia care professionals.

Considering these challenges, caregivers and organizations both identified the same top priorities for action: (1) raising awareness about resources; (2) making services easier to access; and (3) training healthcare providers to better support caregivers and their families. Together, these findings highlight the urgent need to improve caregiver support in Texas by addressing individual and systemic barriers to ADRD-related service availability, access, and use. Categories of recommended strategies include: (1) Enhance outreach and awareness; (2) Simplify service access and increase care navigation; (3) Expand support for caregiver self-care, health, and well-being; (4) Increase the availability of geriatric specialists and the ADRD service workforce; (5) Address cultural and language barriers; and (6) Enhance telehealth and virtual support.