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 Health and Aging

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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.

BACKGROUND AND RATIONALE

The Alzheimer's Association (2025) estimates that 7.2 million Americans are living with Alzheimer's Disease and related dementias (ADRD). According to the Center for Disease Control (2022), Texas, which ranks in the top five highest states of ADRD cases, experienced over ten-thousand deaths related to ADRD in 2022. Close to half of the caregiving provided to older adults with ADRD is unpaid caregiving by family and friends (Alzheimer's Association, 2025). The Alzheimer's Association (2025) values unpaid caregiving provided to patients with ADRD at $413.5 billion nation-wide. In 2024, unpaid caregivers in Texas provided an estimated 1,878 million hours of unpaid care valued at over $33 billion, second only to California (Alzheimer's Association, 2025). The lifetime cost of caregiving, medical care, and daily expenses for an individual with ADRD is estimated to be over $400,000 as of 2024 (Alzheimer's Association, 2025).

There is no known cure for ADRD; however, advances in pharmacologic treatment can delay the progression of ADRD-related symptoms. This means that, despite living longer lives with potentially less severe symptomatology, people living with ADRD may require care from relatives, friends, and/or professionals for longer durations. For unpaid or family caregivers, the physical, mental, and emotional burdens of caregiving can be detrimental to their wellbeing, which may result in poor health outcomes for themselves and the people for which they care (del-Pino-Casado et al., 2021). Despite their best efforts, communities may not provide adequate services, programs, and/or resources to support the diverse needs of unpaid caregivers. Needs assessment may help to better understand the availability of caregiver services in a given community, the utilization of such services by caregivers, and the potentially unmet service needs..

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 caregivers of people living with ADRD. This statewide needs assessment is part of DSHS's larger initiative through the Alzheimer's Disease Program (ADP). The Texas DSHS ADP uses a public health approach to address ADRD based on the Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map.

The activities performed in this statewide needs assessment can provide insights into many of the goals and objectives outlined in the Texas State Plan for Alzheimer's Disease 2024-2029. Directly assessing the needs of unpaid ADRD caregivers can increase the goal of improving and supporting health outcomes and wellbeing of Texans by understanding the availability and utilization of caregiving-related services and supports.

Identifying ADRD caregivers' awareness of and perceived barriers to accessing caregiving services can inform strategies to make resources more accessible to ADRD caregivers at critical time points based on their care recipients' disease state and progression. Understanding caregiver preferences and circumstances can help organizations that support caregivers to identify needed services, determine eligibility, and increase utilization. Additionally, identifying barriers to service use from the perspective of caregivers and service organizations can justify the need to strengthen, support, and sustain the ADRD service workforce in Texas.

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NEEDS ASSESSMENT OVERVIEW

The purpose of this statewide needs assessment was to better understand the availability, accessibility, and use of services for unpaid caregivers of people living with ADRD in Texas. This needs assessment 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.

To address these goals, the aims of this needs assessment were to: (1) increase the availability of data about gaps in services and support, including community-clinical linkages, for caregivers of persons with ADRD across Texas; and (2) increase knowledge about ways to improve sustainable ADRD efforts across Texas.

Stakeholder and community input was incorporated into all aspects of planning for, and conducting, this needs assessment to recruit stakeholders and survey participants through diverse channels and networks across the state to ensure the needs assessment contained a wide representation of dementia types (e.g., Alzheimer's Disease, vascular dementia, Lewy body disease, frontotemporal, Parkinson's disease) and populations of high burden (e.g., East Texas, Hispanic Americans, and rural residents).

Agencies engaged throughout the needs assessment process included, but were not limited to, AgriLife Extension, the Texas Association of Area Agencies on Aging, Texas Chapters of the Alzheimer's Association, Texas Alzheimer's Research and Care Consortium affiliates, Texas Healthy at Home, and Texas Coalitions focused on aging-related issues (e.g., falls, social connection).

DATA COLLECTION METHODS

This needs assessment included two interrelated statewide surveys and a series of four virtual Community Discussion Groups (CDG). These efforts were leveraged to complement and build upon one another to receive comparable information from unpaid ADRD caregivers and organizations that serve and support unpaid ADRD caregivers in Texas.

Online Surveys

Two interrelated cross-sectional surveys were developed to assess aspects of ADRD service/resource demand, availability, accessibility, and utilization. The surveys also gathered perceptions about the adequacy of services/resources, barriers to their use, and community priorities related to ADRD. Both surveys were designed to be brief, yet robust, and include similar items to collect similar information from the vantage point of the two audiences: (1) unpaid ADRD caregivers; and (2) organizations serving unpaid ADRD caregivers. Aspects of both surveys built upon the 2024 Texas Alzheimer's Disease and Related Dementias Caregiver Survey recently conducted by DSHS and the Texas State Plan for Alzheimer's Disease.

Institutional Review Board (IRB) approval was obtained from Texas A&M University for the unpaid ADRD caregiver (#2025-0007) and organization (#2025-0008) surveys. Recruitment for both surveys occurred through interactions with partners and networks as well as social media and emails to networks, listserv, and organizations that serve unpaid ADRD caregivers. The emails contained a link to the URL and asked recipients to forward the message to others to facilitate 'snowballing' recruitment.

For these surveys, a "caregiver" was identified as a person who provides unpaid care or assistance to a relative or friend with ADRD. To be eligible for the caregiver survey, participants were required to: (1) provide unpaid care or assistance to a relative or friend with Alzheimer's Disease or other dementias (ADRD) in the past 6 months; and (2) report that either they and/or their care recipient lived in Texas in the past 12 months. To be eligible for the organization survey, participants were required to represent an organization that: (1) provides programs, services, or resources to unpaid ADRD caregivers; and (2) conducts business in Texas and serves Texas residents.

Eligible participants completed online questionnaires hosted on Qualtrics. After acknowledging the Information Sheet and agreeing to participate in the study, they were able to complete the survey. Each one-time survey took about 10 to 15 minutes for

participants to complete. Participation was voluntary, and no incentives were provided for participation. Participants were able to skip any question they did not wish to answer or exit the survey at any point.

Data were collected for both statewide surveys between January 21 and April 29, 2025. All available data for each variable were included in analyses. It should be noted that, given the lack of monetary incentive and not forcing item responses, the sample size for each question varied based on missing data.

Community Discussion Groups (CDG)

A series of four virtual CDG were hosted in July 2025 to gather more in-depth qualitative perspectives about the needs of unpaid ADRD caregivers, service adequacy and deficits, barriers to service utilization, and needs to improve service delivery. Each CDG was based on the learnings from the two statewide surveys described above.

Institutional Review Board (IRB) approval was obtained from Texas A&M University for the CDG (#2025-0714). Recruitment for CDG occurred through interactions with partners and emails to trusted leaders within target regions. Eligibility for CDG participation required participants to work for an organization that supports and serves unpaid caregivers of people living with ADRD in Texas. Interested participants were asked to sign and return a consent form and complete an abbreviated version of the statewide organization survey prior to the virtual session. Each CDG was audio recorded to facilitate verbatim transcription and thematic analyses. Participants who completed the survey and participated in the CDG received an electronic gift card for $50 for their time.

Four virtual CDG were hosted using Zoom. Two CDG were virtually hosted with organizations serving Region 1, one CDG was virtually hosted with organizations serving Region 4, and one CDG was virtually hosted with organizations serving Region 5 (see Figure 1). Hosting virtual CDG in these geographic areas with high ADRD burden allowed for in-depth perspectives from East Texas and rural communities to reflect about ADRD caregiving services and needs in their community. A total of 29 organization representatives attended a CDG (i.e., 14 in Region 1, seven in Region 4, and eight in Region 5). A variety of entity types were engaged, including representatives from area agencies

on aging, social service organizations, residential facilities, educational institutions, and healthcare organizations.

Each CDG was hosted virtually using Zoom and lasted approximately one hour. Using a virtual CDG facilitation protocol developed for this initiative, the participants were led through a series of interactions based on data elements (or 'learnings') from the statewide needs assessment survey.

Participants independently utilized the 'chat' feature to reflect about the issue, which ensured all participant perspectives were captured for each learning before proceeding. Then, participants were asked to unmute themselves and verbally elaborate about their thoughts. A total of four learnings were included in each virtual CDG session. During the chat and verbal reflections, participants were asked to reflect about whether the learning was true for their region/organization, why this was occurring, and what is needed to address the issue and improve the situation.

Participants' responses for each CDG were captured via chat and audio recording. After transcription, a thematic analysis was performed to identify and report recurring themes identified by CDG participants. This flexible approach was used to give focus to what participants said and the underlying meaning of their responses. Content from each CDG was analyzed independently to facilitate separate and aggregate reporting.

Geospatial Assessment

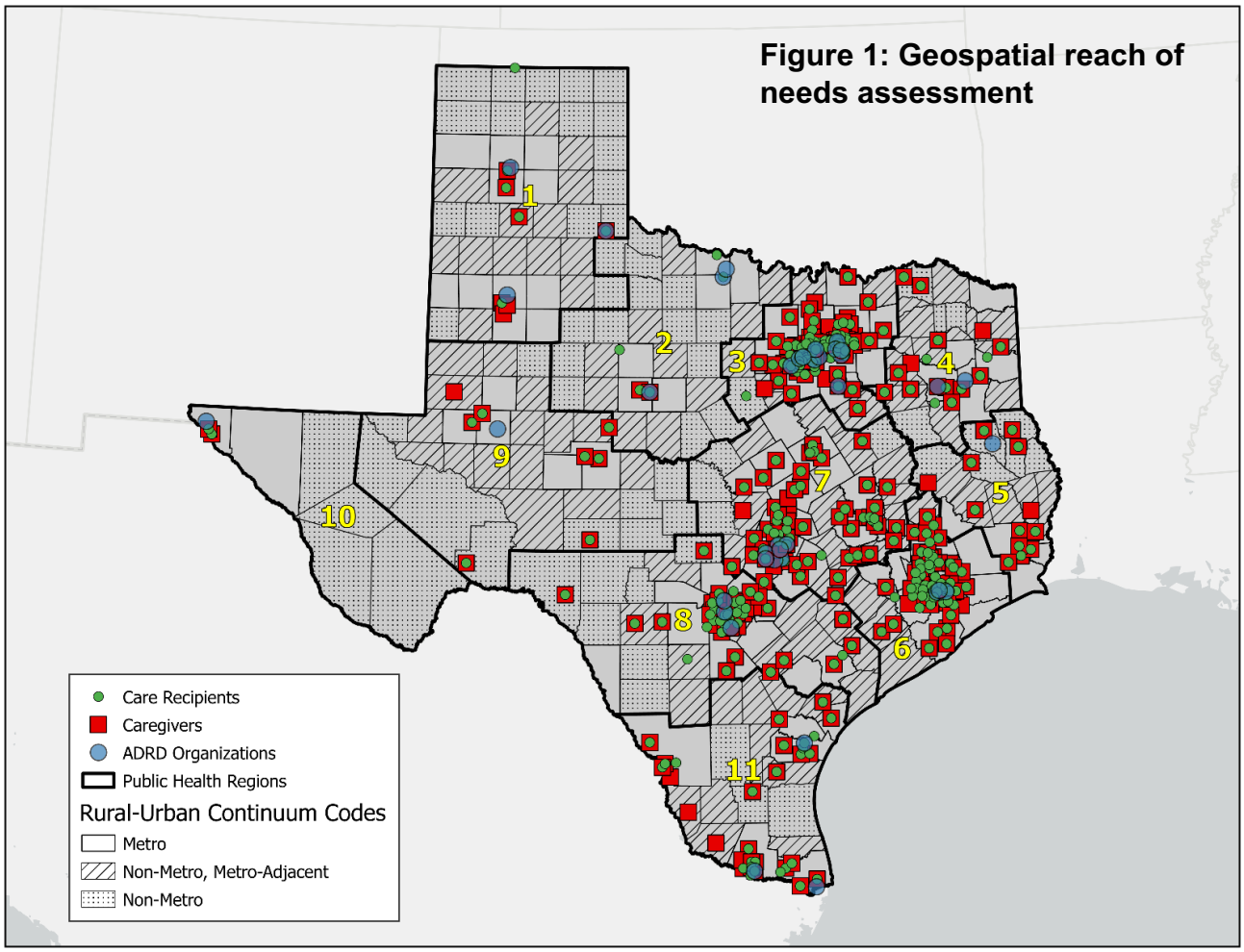
All available data were geocoded based on respondents' 5-digit ZIP Code and the 5-digit ZIP Code of their care recipient. This enabled the dataset to be complemented with county-level data points pertaining to rurality, population composition, income and poverty status, and health status (e.g., percent of population ages 65+ with Alzheimer's Disease). Using these data, layered maps were generated to visualize the location of participating caregivers (and their care recipients) and organizations. When appropriate, caregiver and organization responses were compared by rurality.

FINDINGS

Survey Response Rates and Geospatial Reach

For the caregiver survey, 1,045 individuals initiated the survey, with 789 (75.5%) meeting eligibility criteria. Of those, about 580 (73.5% of eligible participants) contained sufficient data for analyses. For the organization survey, 85 individuals initiated the survey, with 58 (68.2%) meeting eligibility criteria. Of those, about 47 (81.0% of eligible participants) contained sufficient data for analyses.

The map below provides a geospatial representation of the participating caregivers (and their care recipients) and responding service organizations. This map identifies the borders of Texas Public Health Regions. Hash marks represent the county-level rurality. Of the 418 caregivers with valid ZIP Codes, one or more resided in 98 of the 254 Texas counties (38.6%). The largest proportions of caregivers were from Regions 3 (26.1%), 7 (23.4%), 6 (18.2%), and 8 (11.5%). Overall, 83.3% of caregivers resided in metro areas, with 16.7% residing in non-metro areas (13.4% in non-metro, metro adjacent areas and 3.3% in non-metro, non-metro adjacent areas). Of the 58 organization respondents, the largest proportion of organizations were located in Regions 3 (37.9%) and 7 (15.5%).



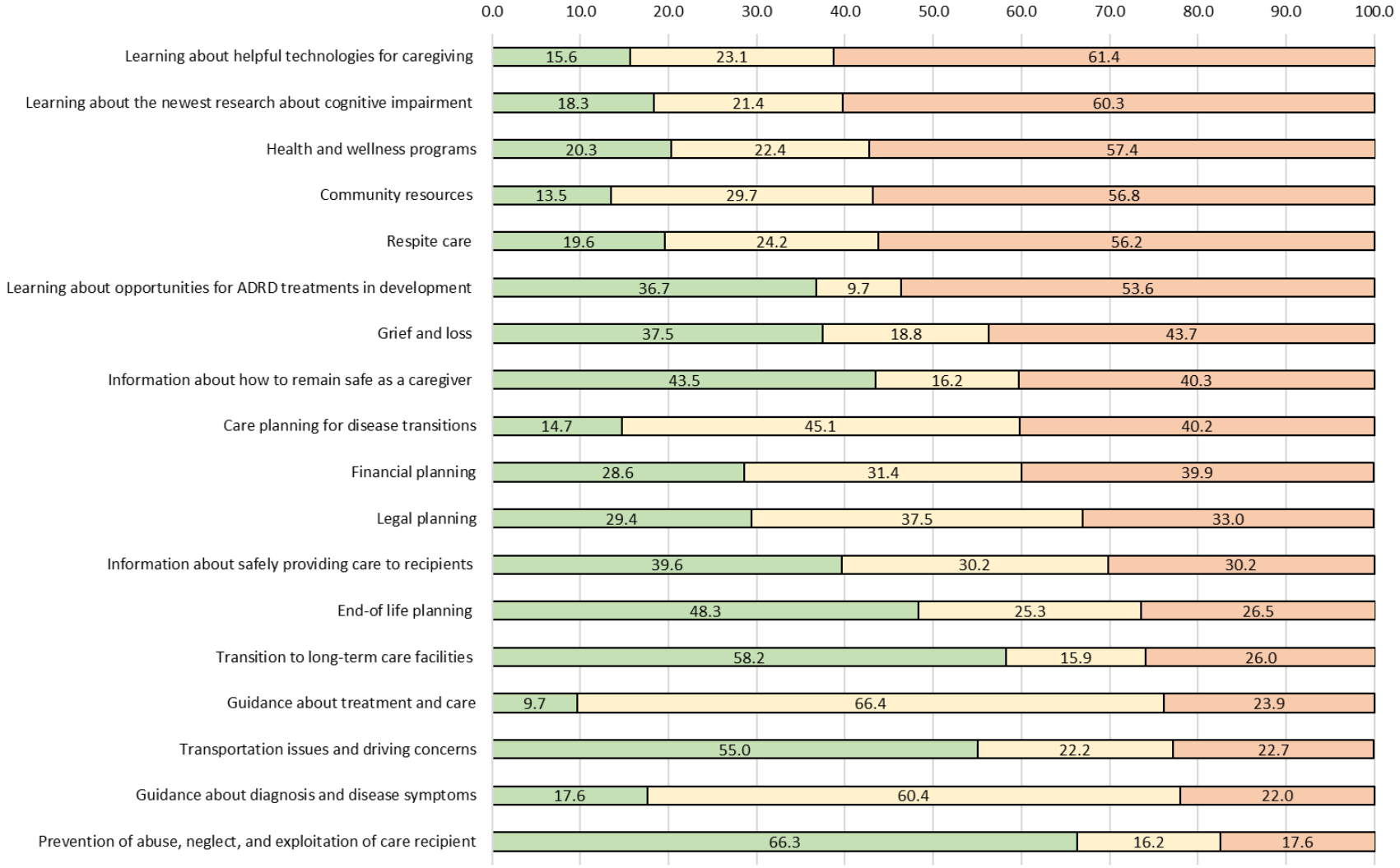
Caregiver Survey Findings

Need and Use of Caregiver Services and Resources

Caregivers were provided with a list of 18 caregiving-related services/resources and asked, “When thinking about your role as a caregiver over the past 6 months, please describe your need for, and use of, the following services and resources.” Their responses could be that they ‘did not need the service/resource’ (green), they ‘needed the service/resource and used it’ (yellow), or they ‘needed the service/resource but did not use it’ (red). Figure 2 reports caregivers’ responses.

The largest proportion of services/resources that were needed but not used included learning about helpful technologies for caregiving (61.4%), learning about the newest research about cognitive impairment (60.3%), health and wellness programs (57.4%), community resources (56.8%), respite care (56.2%), and learning about opportunities for ADRD treatments in development (53.6%). The largest proportion of services/resources needed and used were guidance about treatment and care (66.4%), guidance about diagnosis and disease symptoms (60.4%), and care planning for disease transitions (45.1%). When comparing the need and use of caregiving-related services/resources by caregivers who lived in urban versus rural areas, no significant differences were identified.

Figure 2: Caregiver need for, and use of, services and resources (past 6 months) (%)



Availability and Accessibility of Caregiver Services and Resources

Caregivers were provided with a list of 18 caregiving-related services/resources and asked, "When thinking about the area you live in, please describe if the following services and resources are available and easy to access?" Their responses could be that they believed the service/resource was 'not available' (red), the service/resource was 'available but not easy to access' (yellow), or the service/resource was 'available and easy to access' (green). Figure 3 reports caregivers' responses.

The largest proportion of services/resources believed to not be available were information about ADRD treatments in development (34.9%), technologies for caregiving (29.3%), transportation services (27.5%), and community resources (25.4%). Substantial proportions of caregivers believed that many services were 'available but not easy to access,' with 12 of 18 services/resources ranging between 40.1% and 49.3%.

When comparing the availability and accessibility of caregiving-related services/resources by caregivers who lived in urban versus rural areas, many significant differences were identified (i.e., for 12 of 18 services/resources). Specifically, compared to caregivers in urban areas, caregivers who lived in rural areas were more likely to report information was not available regarding ADRD diagnosis and disease symptoms, ADRD treatments, transitions to long-term care facilities, grief and loss, remaining safe as a caregiver, and safely providing care to recipients. Compared to caregivers in urban areas, caregivers who lived in rural areas were also more likely to report that respite care, community resources, health and wellness programs, research about cognitive impairment, and technologies for caregiving were not available.

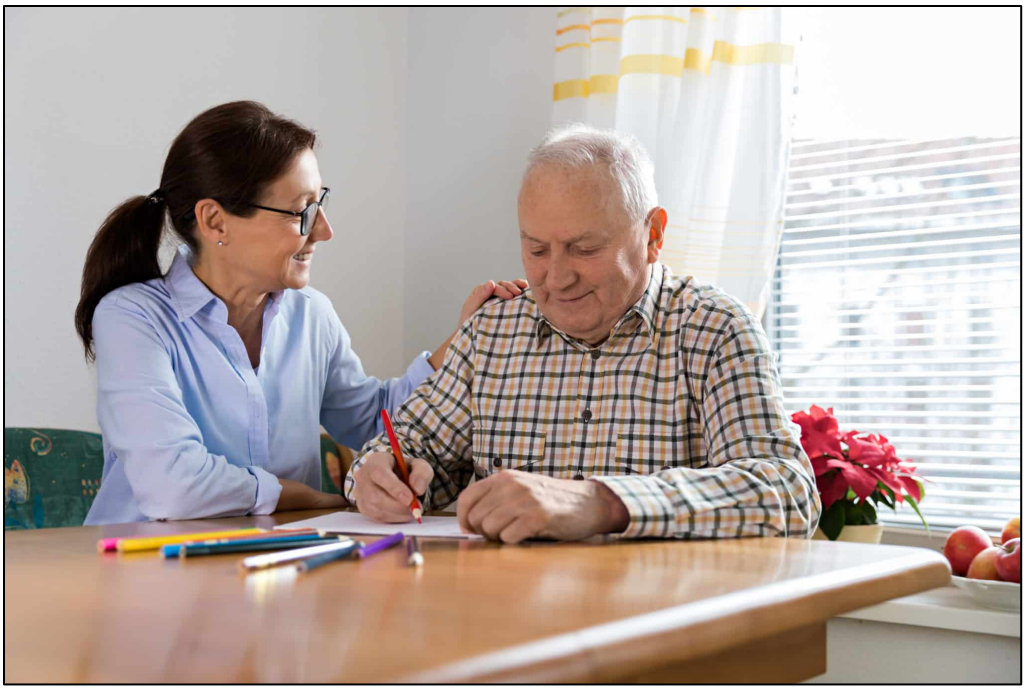
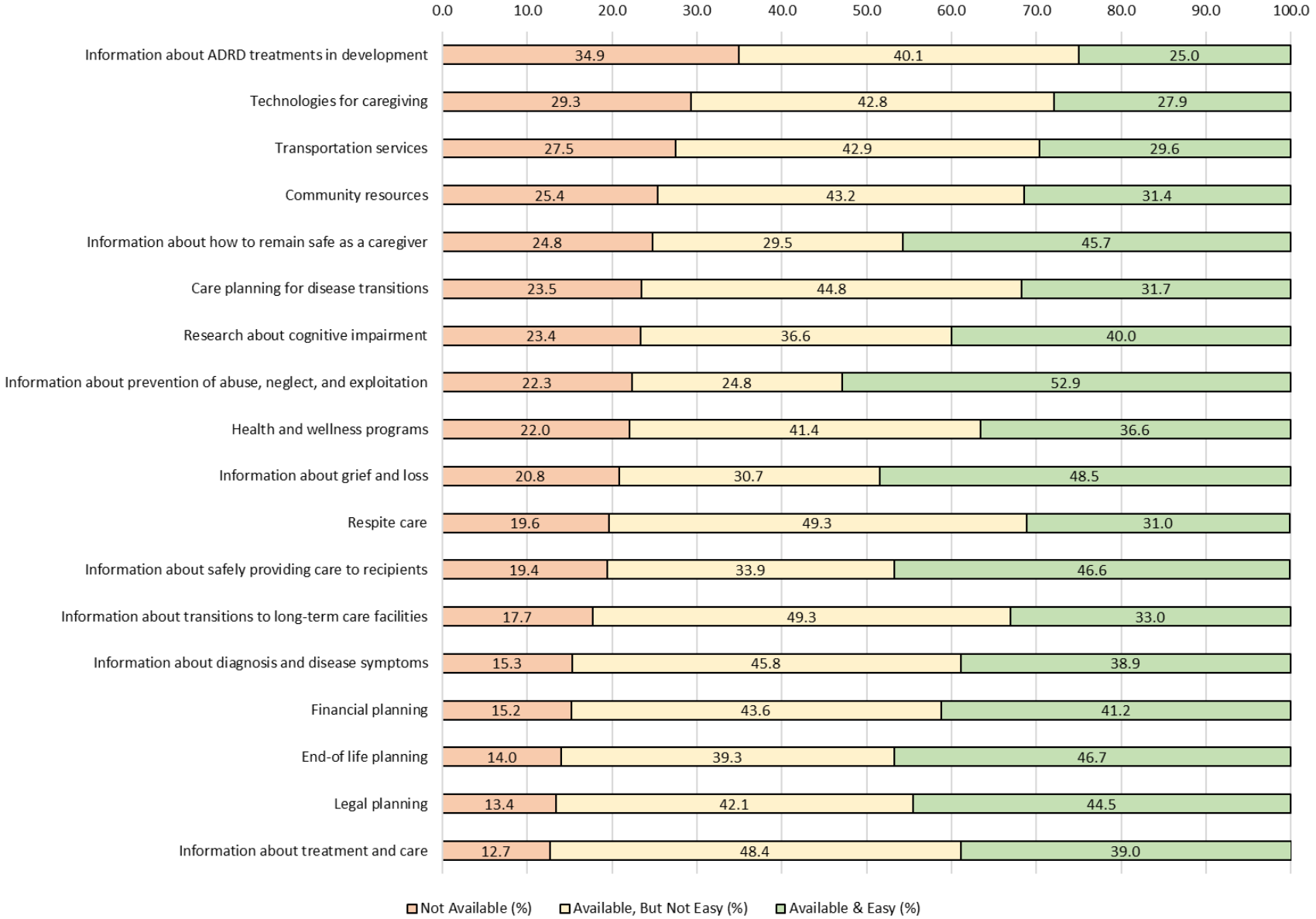


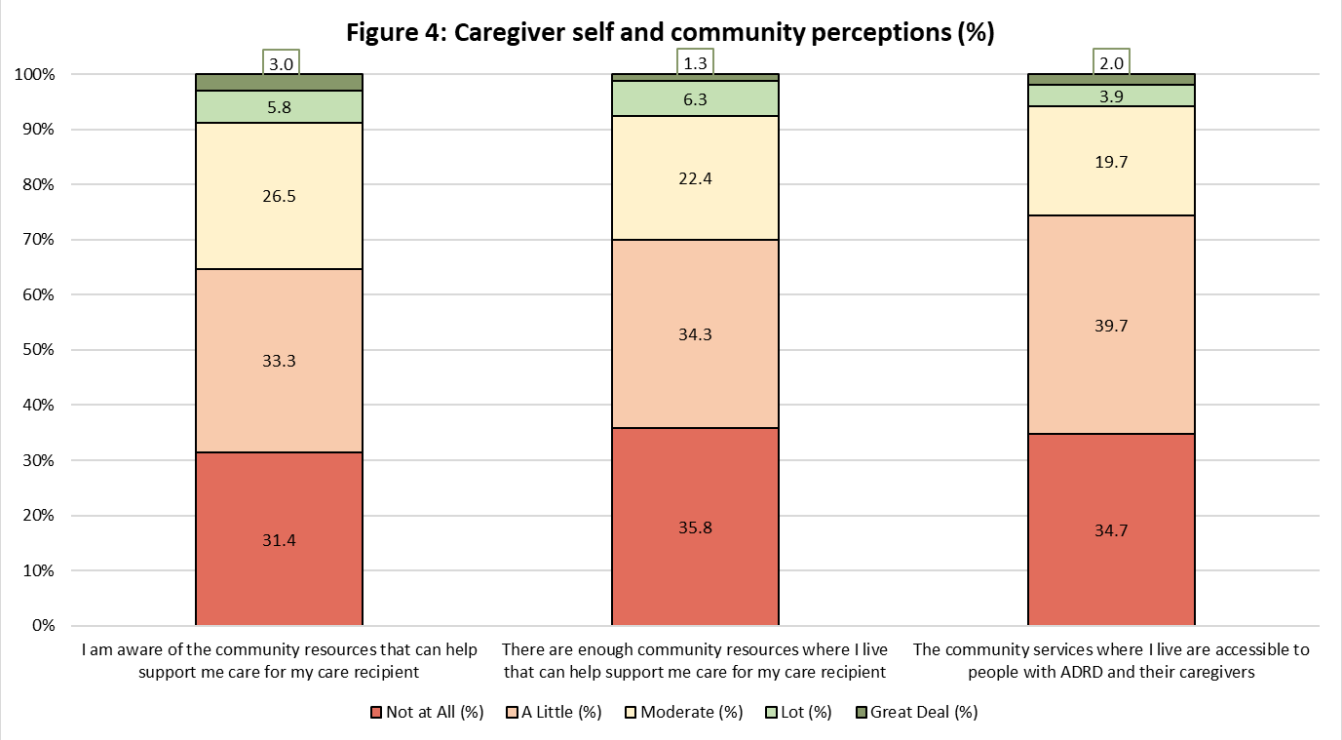
Figure 3: Caregiver beliefs that services and resources are available and easy to access in their area (%)



Caregiver Self and Community Perceptions

Caregivers were asked to indicate the degree to which three statements described the community in which they lived. Their responses could be 'not at all' (deep red), 'a little' (red), 'moderately' (yellow), 'a lot' (light green), and 'a great deal' (deep green). Figure 4 reports caregivers' responses.

Caregivers acknowledged their awareness of community resources that can help support them to care for their care recipient was low (i.e., 31.4% 'not at all,' 33.3% 'a little'). However, caregivers also reported that there were not enough community resources where they live that can help support them to care for their care recipient (i.e., 35.8% 'not at all,' 34.3% 'a little'). Further, caregivers reported that the community services where they live are not highly accessible to people with ADRD and their caregivers (i.e., 34.7% 'not at all,' 39.7% 'a little'). Small proportions of caregivers reported high awareness, that their community had enough resources to support caregiving, and that their community services were accessible, respectively. When comparing these perceptions by caregivers who lived in urban versus rural areas, no significant differences were identified.

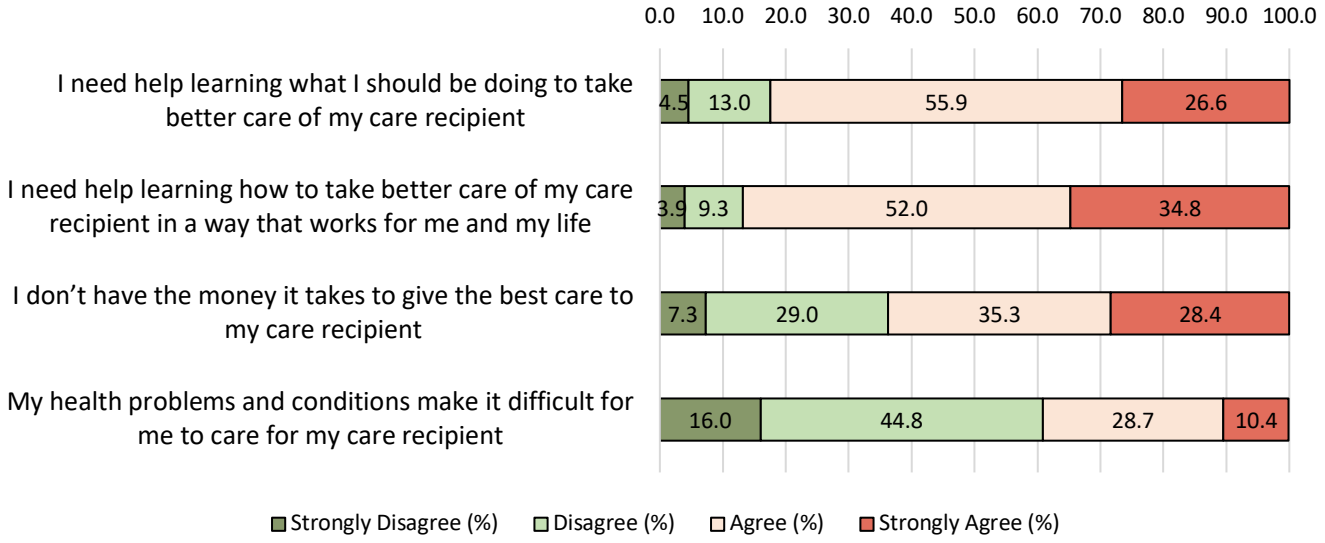


Barriers to Providing Optimal Care

In terms of barriers to providing optimal care to their care recipients, participants were asked to rate their level of agreement with four statements. Their responses could be 'strongly agree' (deep red), 'agree' (red), 'disagree' (light green), and 'strongly disagree' (deep green). Figure 5 reports caregivers' responses.

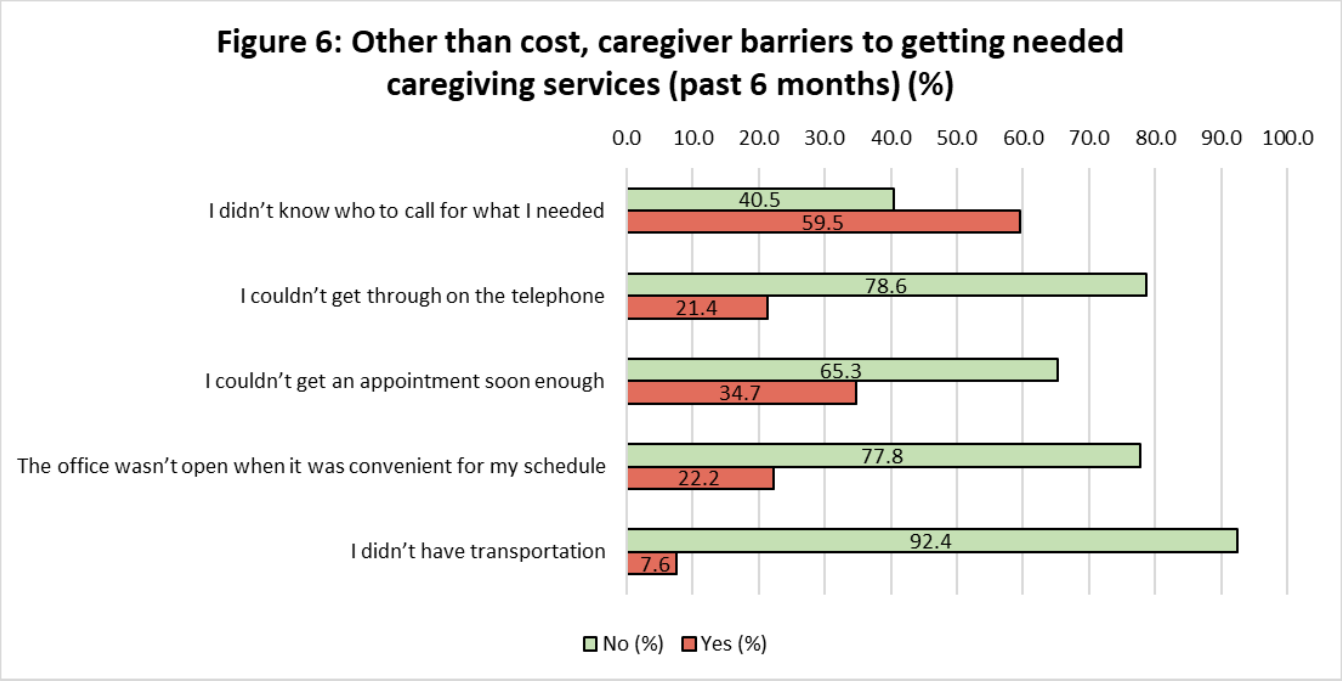
Over 80% of caregivers agreed that they needed help learning what they should do to take better care of their care recipient. Over 86% agreed that they needed help learning how to take better care of their care recipient in a way that works for them and their life. Over 63% of caregivers agreed that they didn't have the money needed to give the best care to their care recipients. Despite reporting that caregiving has negative effects on their health (reported below), only 39.1% of caregivers reported that their health problems and conditions made it difficult for them to care for their care recipient.

Figure 5: Caregiver barriers to providing optimal care (%)



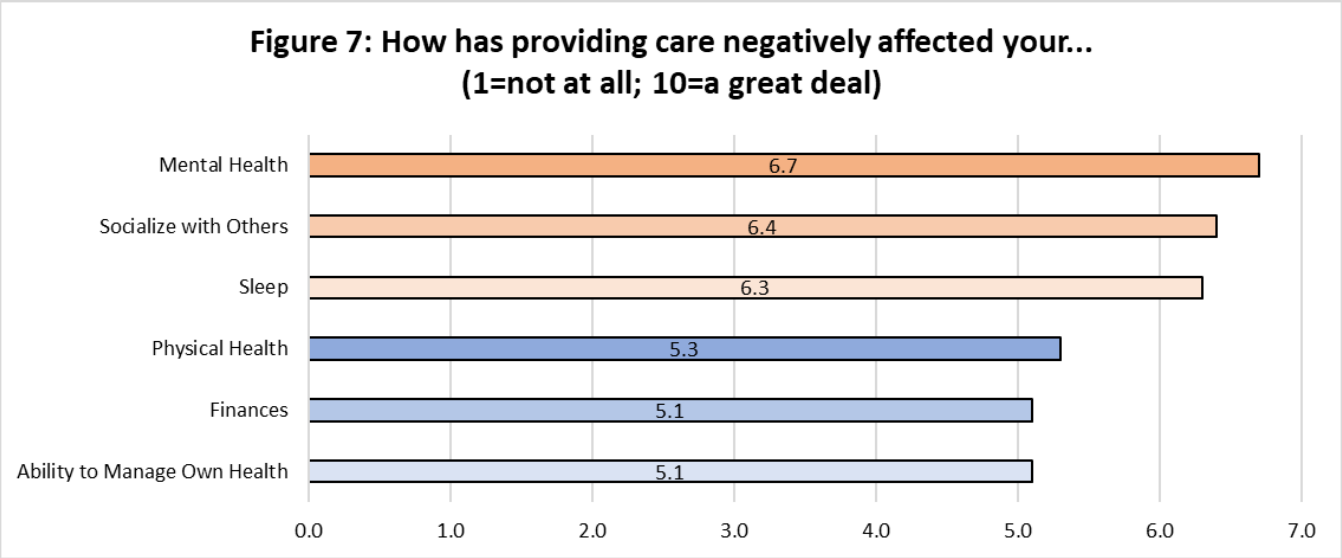
Caregivers were asked, "other than cost, have any of the following delayed you from getting caregiving services you needed in the past 6 months?" They were provided with a list of five non-cost-related barriers. Their responses could 'yes' (red) or 'no' (green). Figure 6 reports caregivers' responses.

The largest proportions of caregivers reported that not knowing who to call for what they needed (59.5%) and being unable to get an appointment soon enough (34.7%) delayed them from getting needed caregiving services. When comparing these barriers to getting services by caregivers who lived in urban versus rural areas, no significant differences were identified.



Impact of Caregiving on Health and Wellness

Caregivers were asked to rate the degree to which providing care or assistance to their care recipient negatively affected their health and wellness. Responses were recorded on a scale from 1 ('not at all') to 10 ('a great deal'). As seen in Figure 7, on average, caregivers reported moderate-to-high negative effects, especially for their mental health (6.7), ability to socialize with others (6.4), and sleep (6.3).

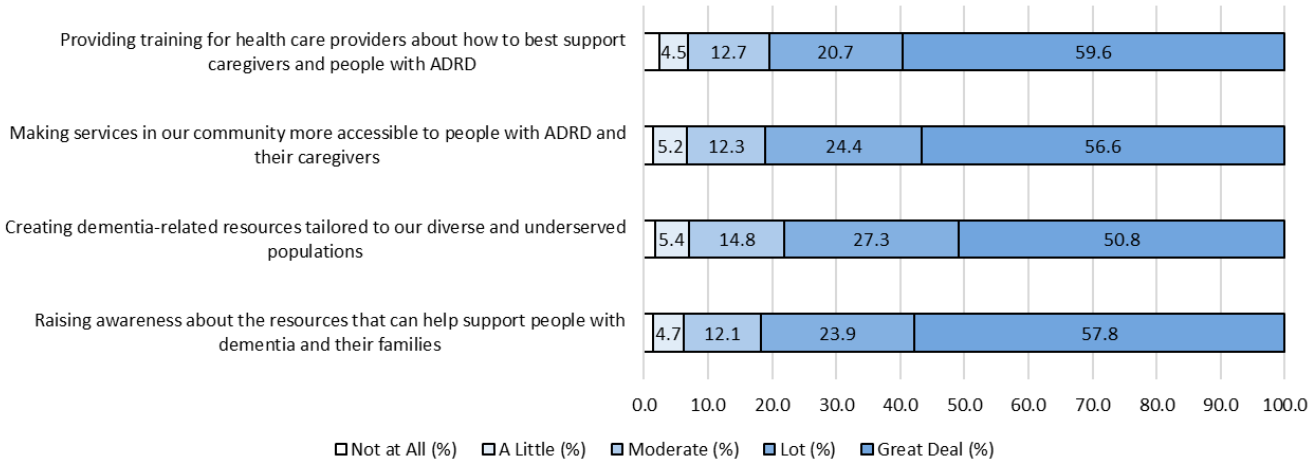


Caregiver Community Priorities

Caregivers were provided with a list of 4 statements and asked to report the degree to which they believed each should be a priority for action in their community. Figure 8 reports caregivers' responses.

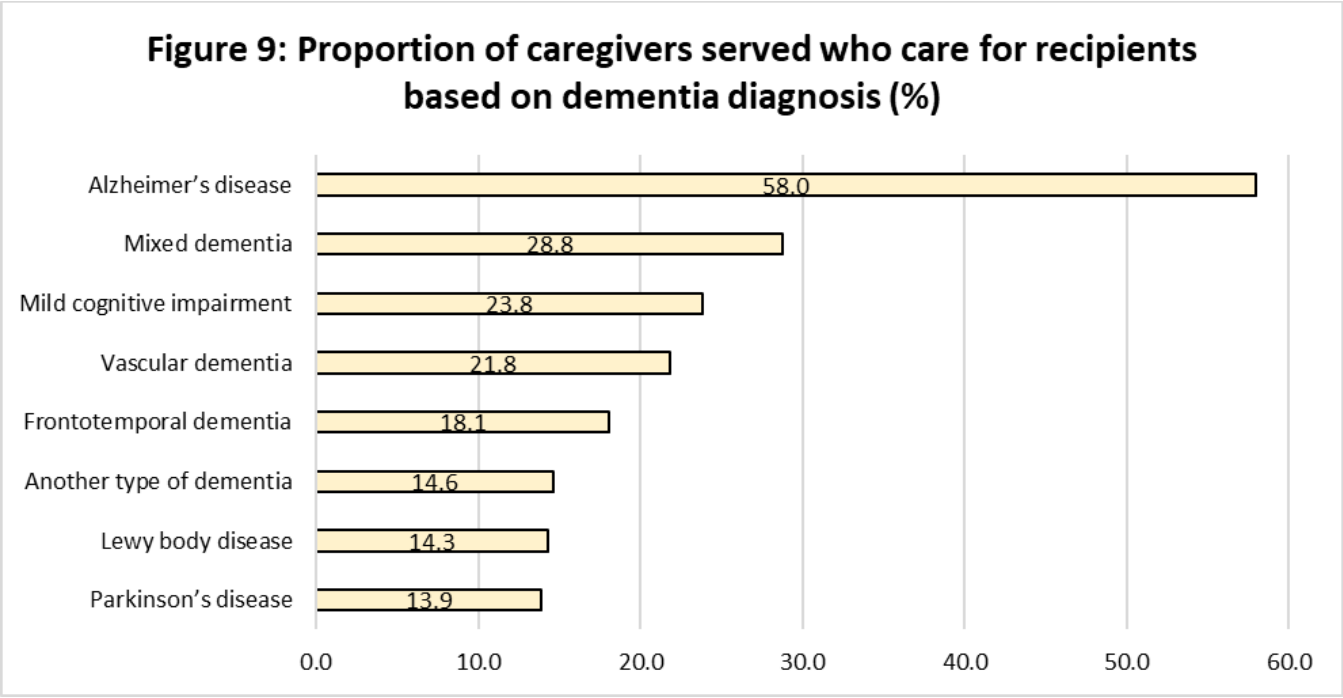
Most caregivers reported that each statement should be an action priority, with the highest support surrounding training healthcare providers about how to best support caregivers and people with ADRD (i.e., 59.6% 'a great deal'), raising awareness about resources to support people with ADRD and their families (i.e., 57.8% 'a great deal'), and making services more accessible to people with ADRD and their caregivers (i.e., 56.6% 'a great deal').

Figure 8: Caregiver desired action priorities in their community (%)



Organization Survey Findings

Organizations were asked to report the proportion of ADRD caregivers that have care recipients with different dementia diagnoses. As seen in Figure 9, the largest proportions of caregivers served provided care for individuals with Alzheimer's Disease (58.0%), mixed dementia types (28.8%), mild cognitive impairment (23.8%), and vascular dementia (21.8%).

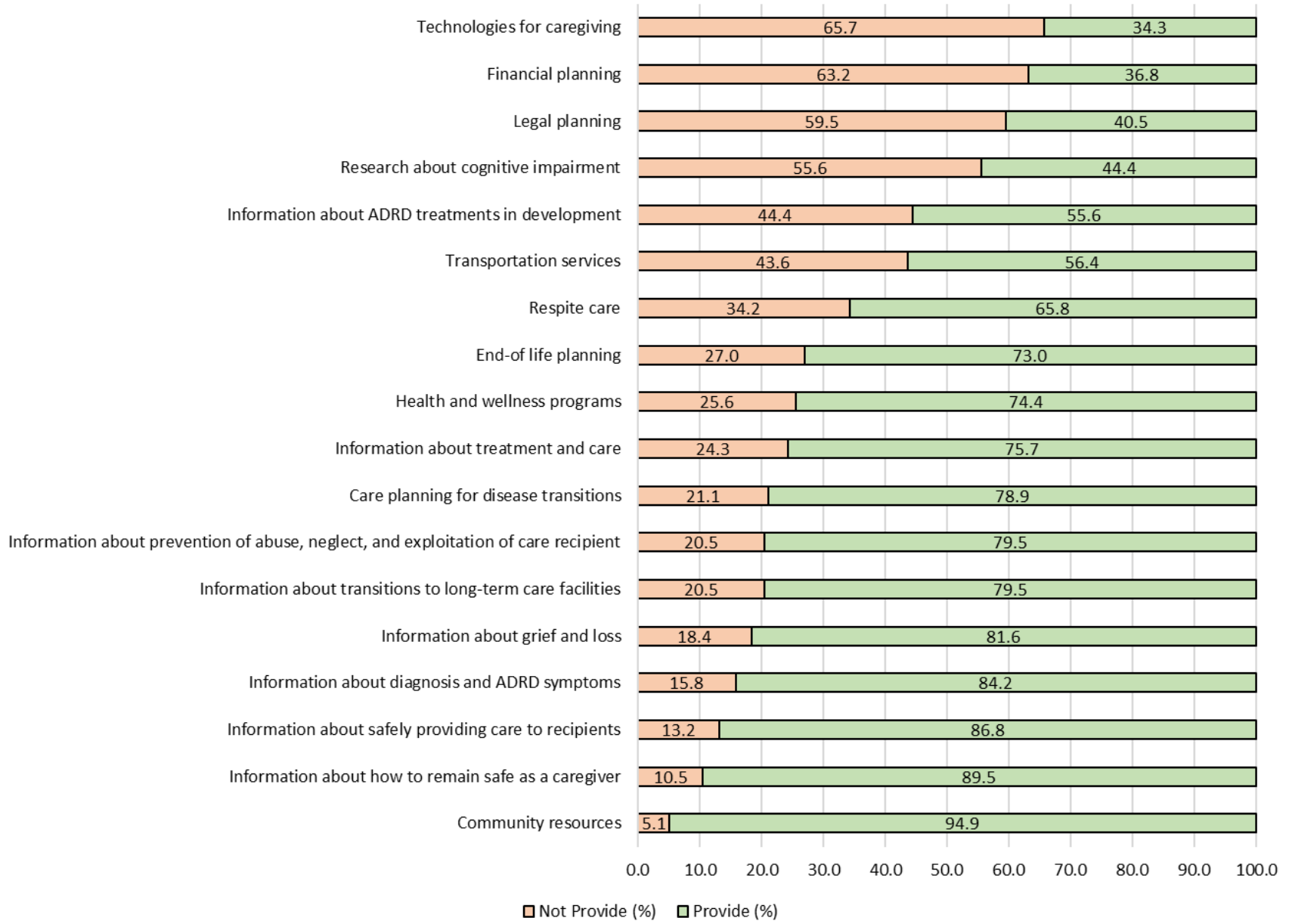


Organization Services

Organizations were asked to report the services they provide to unpaid caregivers from a list of 18 services/resources. They responded if their organization "provided" (green) or 'did not provide' (red) each service/resource. Figure 10 reports organizations' responses.

Large proportions of organizations reported offering 11 of the 18 services (i.e., ranging from 73.0% for end-of-life planning to 94.9% for community services). The largest proportions of organizations reported not providing technologies for caregiving (65.7%), financial planning (63.2%), legal planning (59.5%), research about cognitive impairment (55.6%), information about ADRD treatments in development (44.4%), transportation services (43.6%), and respite care (34.2%).

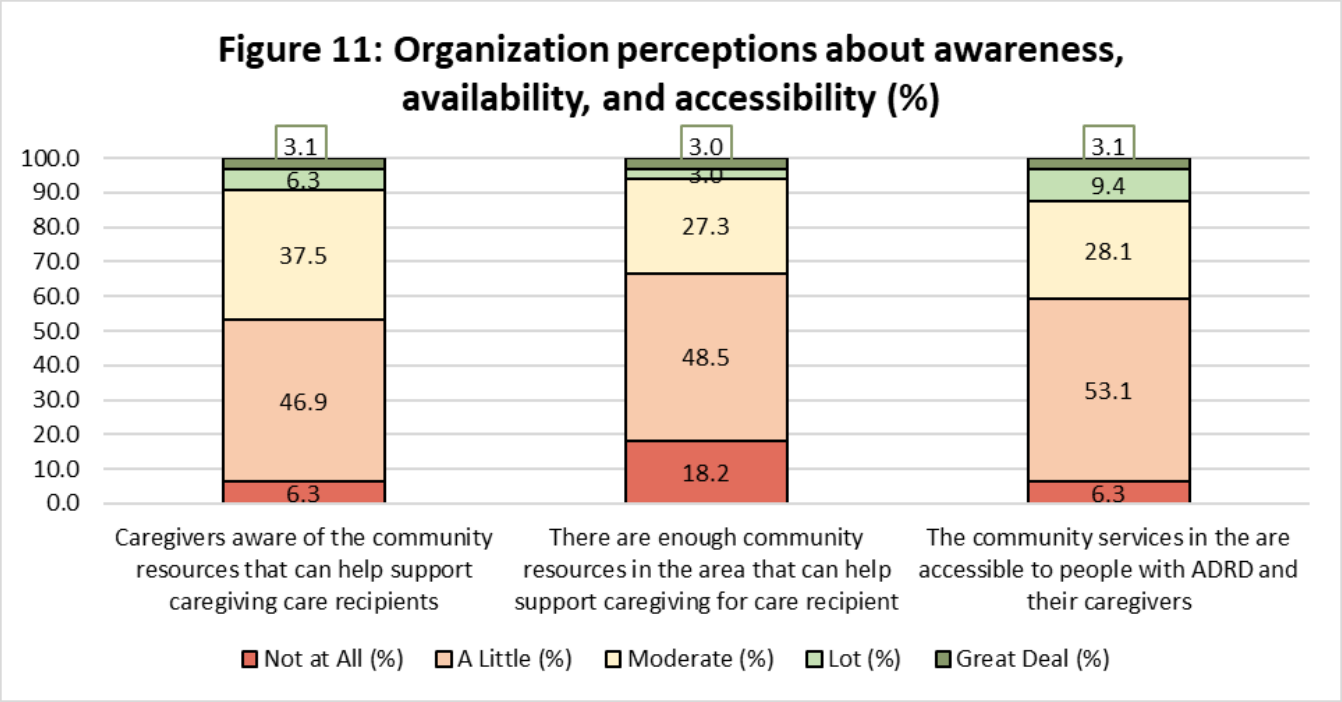
Figure 10: Services organizations provide to caregivers (%)



Organization Perceptions of Caregivers and Community Resources

Organizations reported the degree to which three statements described their service area. Their responses could be 'not at all' (deep red), 'a little' (red), 'moderately' (yellow), 'a lot' (light green), and 'a great deal' (deep green). Figure 11 reports organizations' responses.

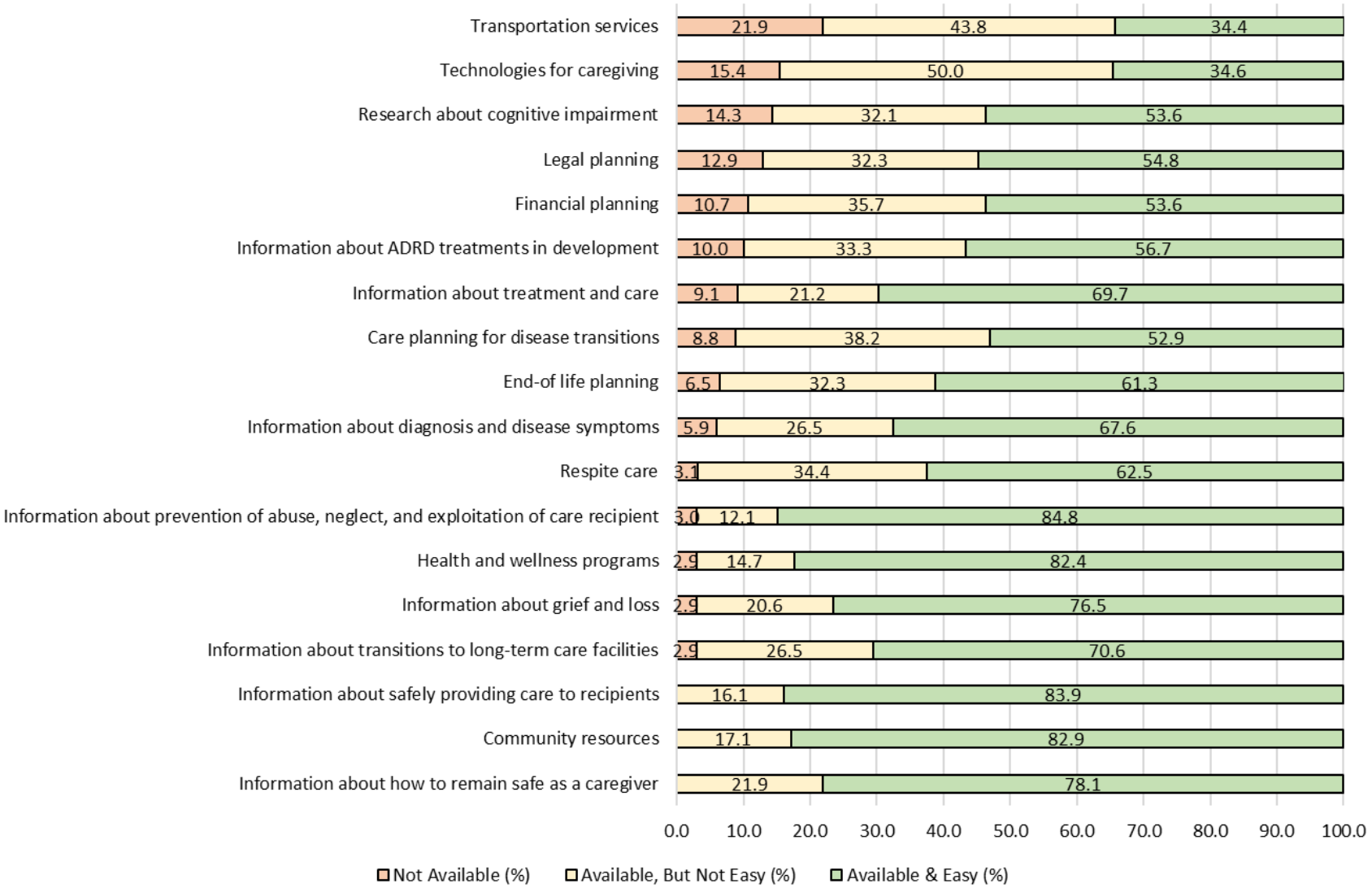
Over half (53.1%) of organizations believed that caregivers had low awareness of community resources that can help support them to care for their care recipient (i.e., 6.3% 'not at all,' 46.9% 'a little'). However, organizations also reported that there were not enough community resources in their service area to help support caregivers to care for their care recipient (i.e., 18.2% 'not at all,' 48.5% 'a little'). Further, organizations reported that the community services are not highly accessible to people with ADRD and their caregivers (i.e., 6.3% 'not at all,' 53.1% 'a little'). Small proportions of organizations reported that caregivers had high awareness, that their community had enough resources to support caregiving, and that community services were accessible, respectively.



Organization Perceptions of Service Availability and Accessibility

Organizations were provided with a list of 18 caregiving-related services/resources and asked, "When thinking about your organization's service area, please describe if the following services and resources are available and easy to access for caregivers of individuals with ADRD." Their responses could be that they believed the service/resource was 'not available' (red), the service/resource was 'available but not easy to access' (yellow), or the service/resource was 'available and easy to access' (green). Figure 12 reports organizations' responses.

Figure 12: Organization beliefs that services and resources are available and easy to access in their area (%)



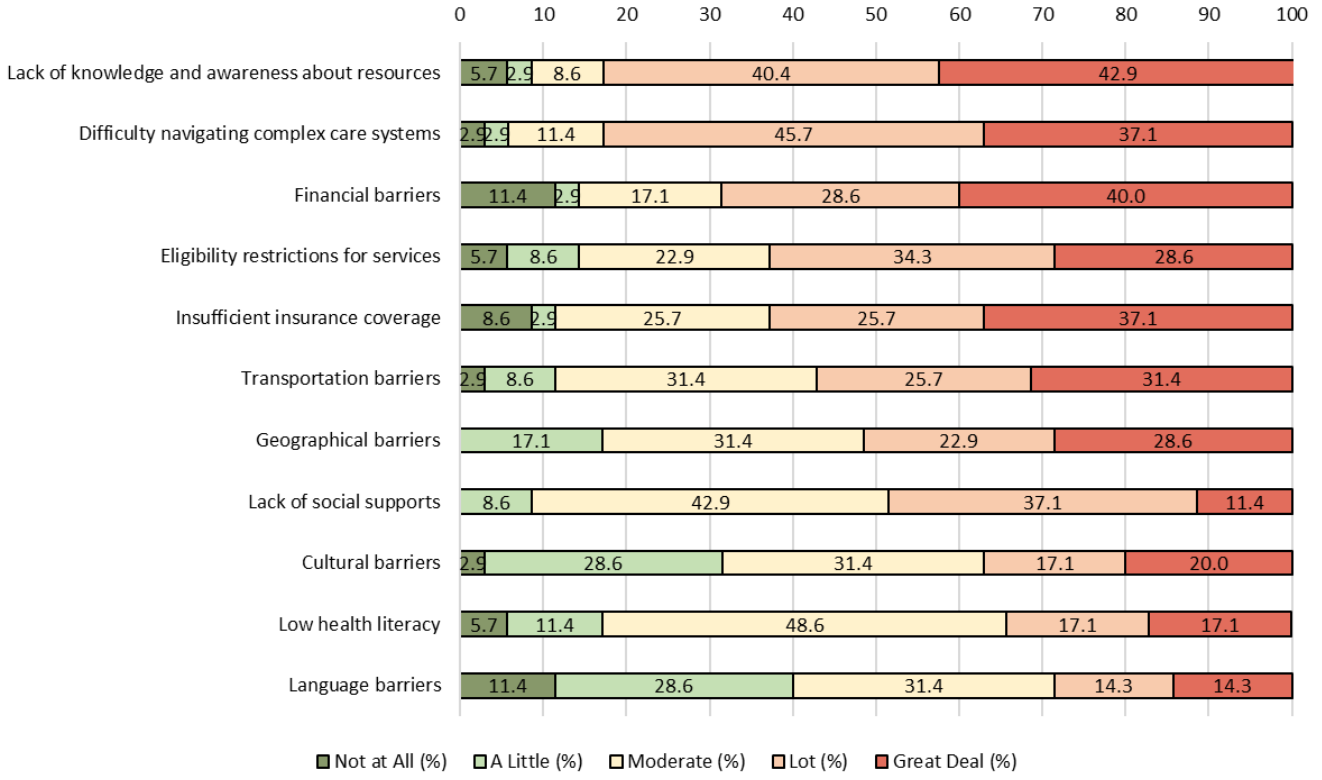
The largest proportion of services/resources believed to not be available were transportation services (21.9%), technologies for caregiving (15.4%), research about cognitive impairment (14.3%), and legal planning (12.9%). Substantial proportions of organizations believed that many services were 'available but not easy to access,' with 9 of 18 services/resources ranging between 32.1% (research about cognitive impairment) and 50.0% (technologies for caregiving). Compared to caregivers' perceptions, larger proportions of organizations reported services/resources to be 'available and easy to access.'

Organization Perceptions About Caregiver Barriers and Needs

Organizations were asked to reflect about 11 barriers for caregivers that may affect their access to caregiving services. Their responses could be 'not at all' (deep green), 'a little' (light green), 'moderately' (yellow), 'a lot' (red), and 'a great deal' (deep red). Figure 13 reports organizations' responses.

Large proportions of organizations believed that lack of knowledge and awareness about resources (i.e., 40.4% 'a lot,' 42.9% 'a great deal'), difficulty navigating complex care systems (i.e., 45.7% 'a lot,' 37.1% 'a great deal'), financial barriers (i.e., 28.6% 'a lot,' 40.0% 'a great deal'), eligibility restrictions (i.e., 34.3% 'a lot,' 28.6% 'a great deal'), and insufficient insurance coverage (i.e., 25.7% 'a lot,' 37.1% 'a great deal') were the most substantial barriers affecting caregivers' access to services.

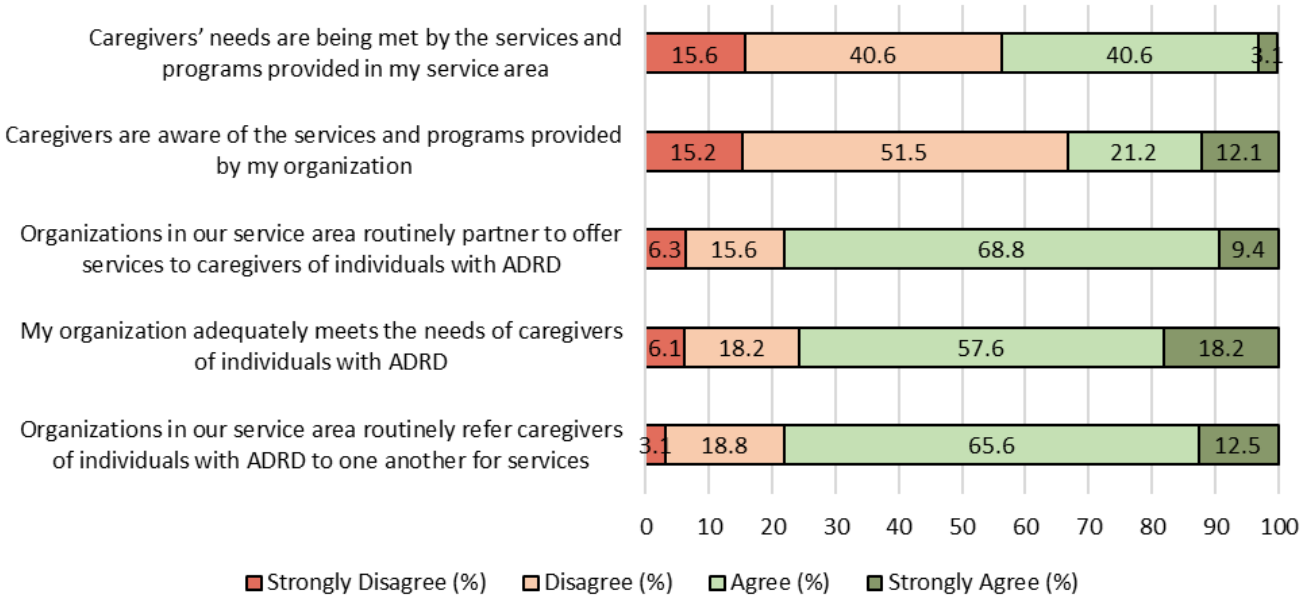
Figure 13: Organization perceptions about barriers for caregivers that affect their access to caregiving services (%)



Organizations were asked to rate their level of agreement with five statements related to meeting caregiver needs. Their responses could be ‘strongly agree’ (deep green), ‘agree’ (light green), ‘disagree’ (red), and ‘strongly disagree’ (deep red). Figure 14 reports organizations’ responses.

Over 65% of organizations disagreed that caregivers were aware of the services and programs provided by their organization. Over 56% of organizations disagreed that caregivers’ needs are being met by the services and programs provided in their service area.

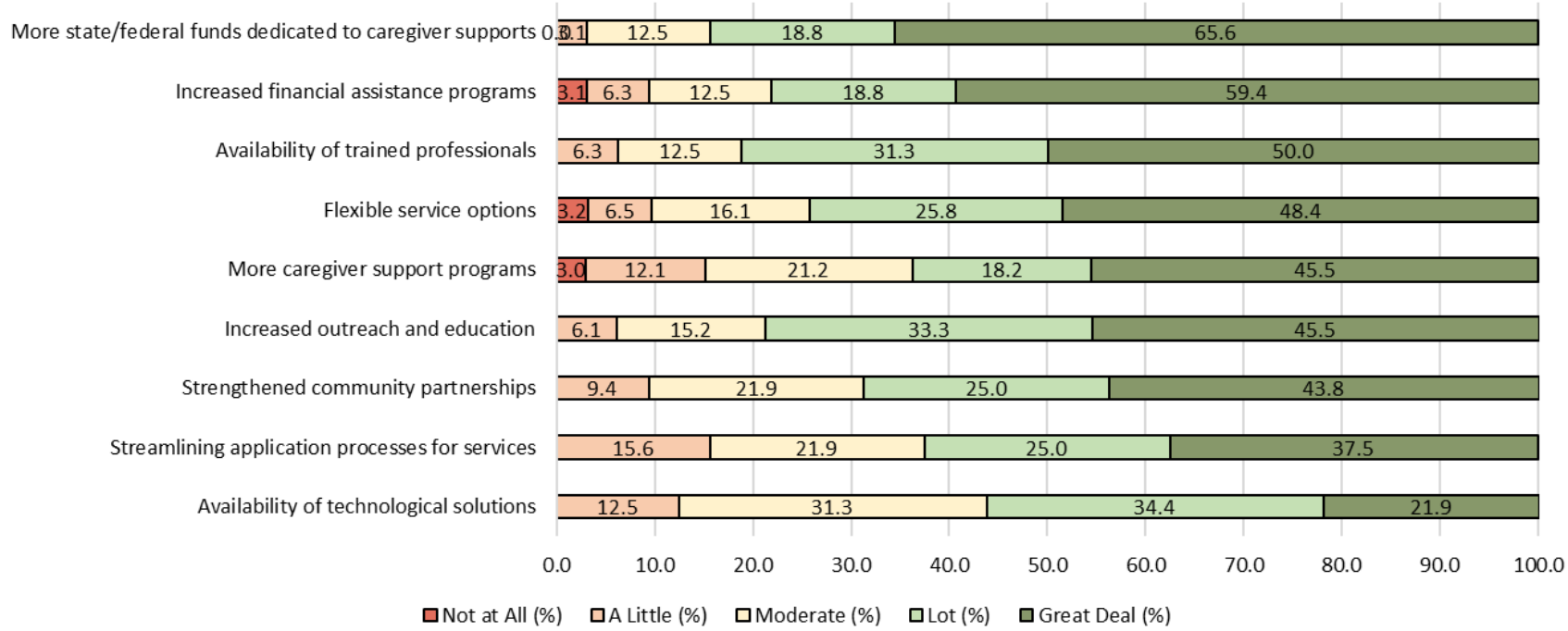
Figure 14: Organization perceptions about meeting caregiver needs (%)



Organizations were asked, "When thinking about your organization's service area, to what degree do you believe the following would increase support to unpaid caregivers of individuals with ADRD?" They were presented with a list of nine services, resources, and strategies. Their responses could be 'not at all' (deep red), 'a little' (red), 'moderately' (yellow), 'a lot' (light green), and 'a great deal' (deep green). Figure 15 reports organizations' responses.

Overall, large proportions of organizations believed that all nine services, resources, and strategies would increase support for caregivers 'a lot' or 'a great deal.' The services, resources, and strategies that organizations believed would increase support for caregivers less (i.e., 'not at all,' 'a little,' or 'moderately') included availability of technology (43.8%), streamlining the application processes for services (37.5%), and more caregiver support programs (36.3%).

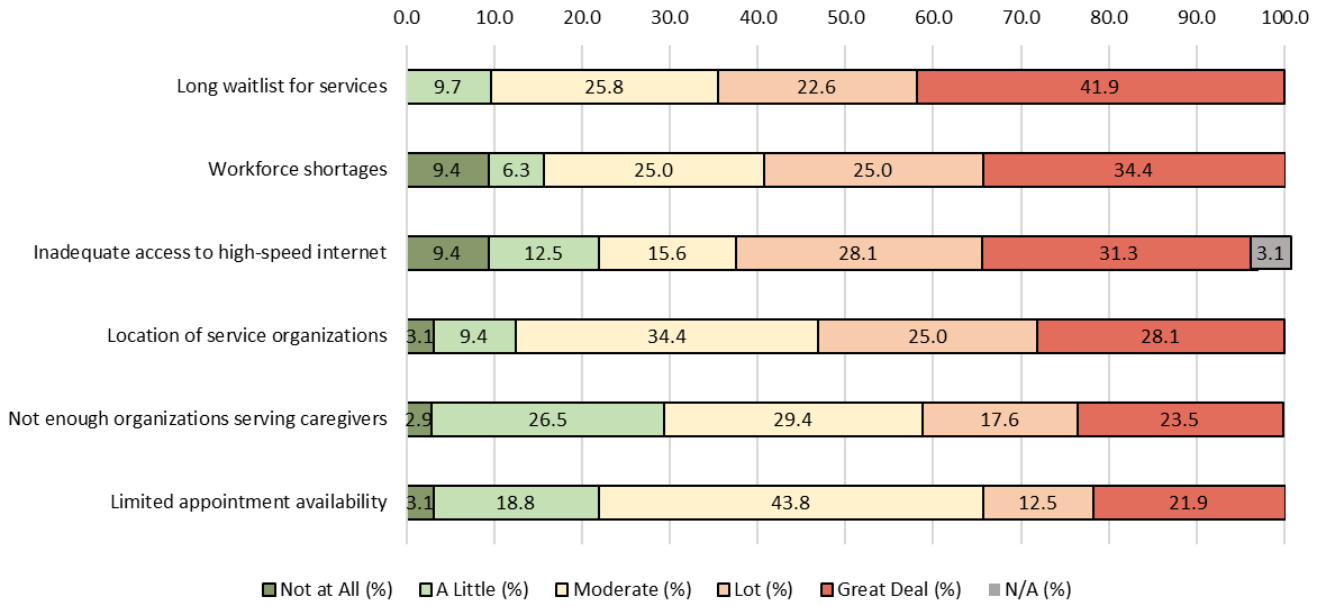
Figure 15: Organization beliefs about the degree services would increase support for caregivers (%)



Organizations were asked to reflect about six organizational and logistical barriers that may affect caregivers' access to caregiving services. Their responses could be 'not at all' (deep green), 'a little' (light green), 'moderately' (yellow), 'a lot' (red), and 'a great deal' (deep red). Figure 16 reports organizations' responses.

Large proportions of organizations believed that long waitlists for services (i.e., 22.6% 'a lot,' 41.9% 'a great deal'), workforce shortages (i.e., 25.0% 'a lot,' 34.4% 'a great deal'), inadequate access to high-speed internet (i.e., 28.1% 'a lot,' 31.3% 'a great deal'), and location of service organizations (i.e., 25.0% ''a lot,' 28.1% 'a great deal') were the most substantial barriers to caregivers accessing caregiving services.

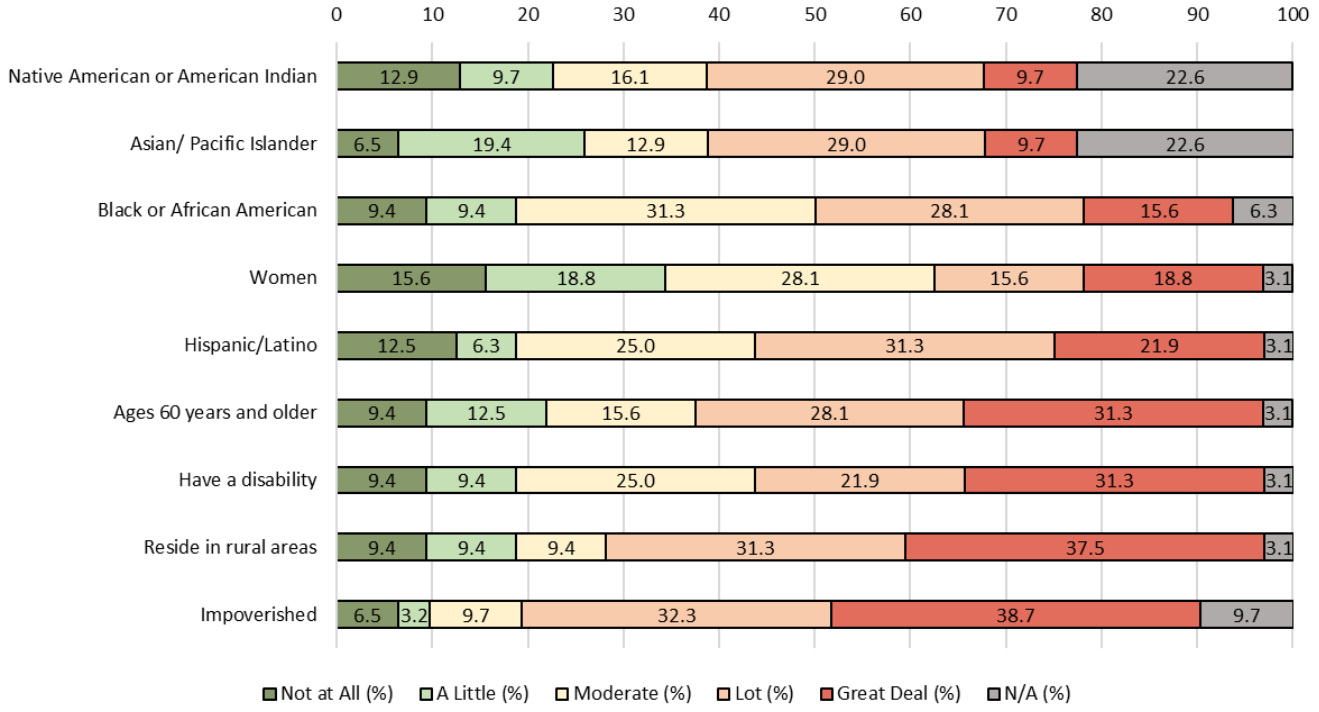
Figure 16: Organization perceptions about barriers for caregivers that affect their access to caregiving services (%)



Organizations were asked to think about whether barriers disproportionately impact any particular caregiver groups. Their responses could be 'not at all' (deep green), 'a little' (light green), 'moderately' (yellow), 'a lot' (red), and 'a great deal' (deep red). Figure 17 reports organizations' responses.

Large proportions of organizations believed that impoverished caregivers (i.e., 32.3% 'a lot,' 38.7% 'a great deal'), caregivers residing in rural areas (i.e., 31.3% 'a lot,' 37.5% 'a great deal'), caregivers with disabilities (i.e., 21.9% 'a lot,' 31.3% 'a great deal'), caregivers ages 60 years and older (i.e., 28.1% 'a lot,' 31.3% 'a great deal'), and Hispanic/Latino caregivers (i.e., 31.3% 'a lot,' 21.9% 'a great deal') had barriers that most disproportionately impacted them.

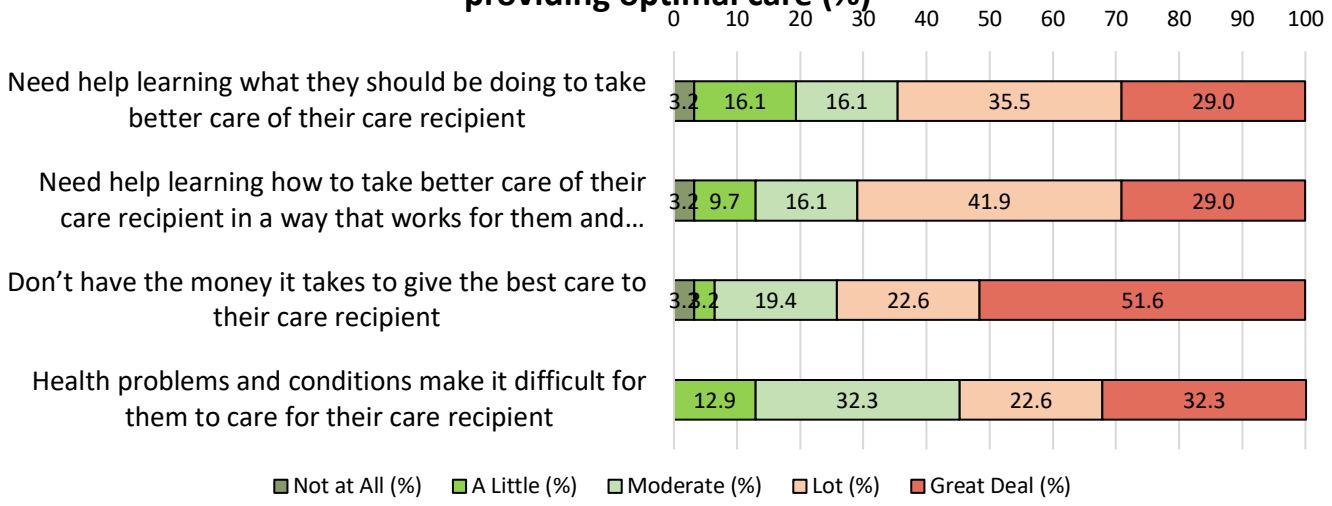
Figure 17: Organization perceptions about disproportionate caregiver barriers by characteristic (%)



In terms of caregivers' barriers to providing optimal care to their care recipients, organizations were asked to rate their level of agreement with four statements. Their responses could be 'not at all' (deep green), 'a little' (light green), 'moderately' (yellow), 'a lot' (red), and 'a great deal' (deep red). Figure 18 reports organizations' responses.

A large proportion of organizations believed that caregivers didn't have the money needed to give the best care to their care recipients (i.e., 22.6% 'a lot,' 51.6% 'a great deal'), needed help learning how to take better care of their care recipient in a way that works for them and their life (i.e., 41.9% 'a lot,' 29.0% 'a great deal'), and needed help learning what they should do to take better care of their care recipient (i.e., 35.5% 'a lot,' 29.0% 'a great deal').

Figure 18: Organization perceptions about caregiver barriers to providing optimal care (%)

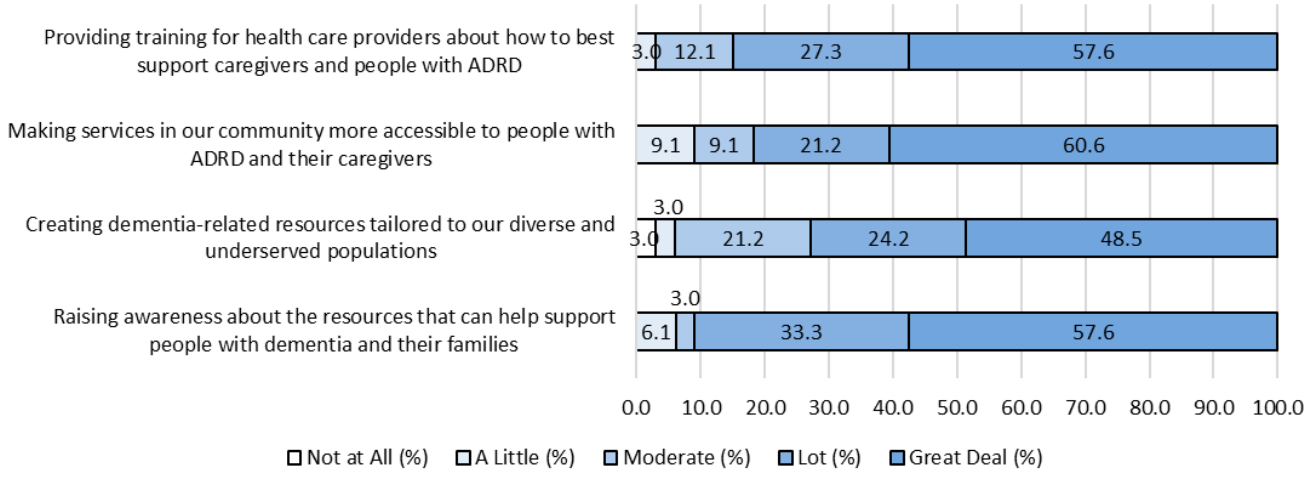


Organization Caregiver Action Priorities

Organizations were provided with a list of four statements and asked to report the degree to which they believed each should be a priority for action in their community. Figure 19 reports organizations' responses.

Similar to caregivers, most organizations reported that each statement should be an action priority, with the highest support surrounding making services more accessible to people with ADRD and their caregivers (i.e., 60.6% 'a great deal'), training healthcare providers about how to best support caregivers and people with ADRD (i.e., 57.6% 'a great deal'), and raising awareness about resources to support people with ADRD and their families (i.e., 57.6% 'a great deal'). Caregivers and organizations shared their beliefs that all four actions should be priorities in their communities.

Figure 19: Organization preferred action priorities in their service areas (%)



CDG Findings

Six common themes emerged from the four CDG. Descriptions of the theme tenets and relevant quotes are provided below. Note that most/all of these themes are interrelated and built upon one another.

Theme 1: Caregiver burden and prioritization of care recipients over self

CDG participants expressed that caregivers often feel overwhelmed and prioritize their loved one's needs above their own, which leaves little time or energy for self-care. They expressed that caregivers must often balance a variety of responsibilities (e.g., work, family, caregiving, their own health). This can cause them to burn out and experience emotional exhaustion, which leads them to neglect their own needs and well-being. Interestingly, when shown survey learnings about caregivers 'needing but not using' services and resources, CDG participants suggested that the caregivers they interact with are so consumed and focused on their caregiving duties (or care recipients' needs) that they are often unable to access resources that could help them and their situation (e.g., respite care, health/wellness programs). Caregivers need support systems for self-care to allow them to better balance care responsibilities with their own well-being.

- "Caregivers are stretched thin and have limited bandwidth."
- "Caregivers don't want to burden others. They feel it is their personal responsibility to care for their loved one."
- "They are already managing caregiving responsibilities without adequate support or time for self-care."
- "Even when they know that resources are available to them, it doesn't necessarily mean that it's always conducive to use those resources. Sometimes the learning curve itself about how to use resources can be really steep."
- "We're asking caregivers to not only take care of the person with dementia but also take care of their family, their job, and their house. It's simply too much for one person to handle. It's like juggling five balls in the air at once."
- "There's no time for a caregiver to take care of themselves—it's all about taking care of the person they love. Even when services are available, they just don't have the bandwidth to use them."

Theme 2: Gaps in awareness and issues with accessibility

CDG participants expressed that caregivers are often unaware of available services and resources because of "less than ideal" outreach and fragmented communication. They expressed that many caregivers have limited knowledge about available resources, which can lead to missed opportunities to get the assistance they need in a timely manner. Even if caregivers are aware that services exist, and they are eligible to receive them, caregivers frequently experience logistical barriers when attempting to access services. This is especially true in rural and geographically isolated areas. CDG participants expressed that caregivers can be unsure of "where to turn" after a loved one is diagnosed. Even when organizations

disseminate information in the community, caregivers have limited awareness about what resources they need, what services are available, and how to access those services. Caregivers would benefit from wide-reaching awareness campaigns with simple information that can avoid "overwhelming or bombarding" caregivers with too many options. Targeted outreach efforts led by community-based organizations and trusted leaders like community health workers can help "bridge the gap between services being offered and the caregivers who need them."

- "I think people don't use services because they either don't know what's available to them or can't get a hold of the right person."
- "Even when organizations actively try to spread awareness, it's still a challenge to reach caregivers."
- "They don't know what they're eligible for. It's all a guessing game."
- "We serve a catchment area that spans over 1.5 million people across a vast region. Getting help to rural caregivers is a massive logistical challenge. It's not just a matter of needing services; it's about accessibility. How do we make sure they can even reach those services?"
- "The travel costs are real—fuel, lost wages, time off work. For caregivers already struggling financially, this adds a huge burden. It's a barrier they often can't overcome."
- "Some caregivers I talk to say they feel "bounced around" between service providers. They're like "deer in the headlights," unsure of what steps to take. They need trusted navigators to guide them through these complicated service systems."
- "Referrals are too complicated, and by the time they get that 3rd referral, they're overwhelmed and give up."
- "People don't have transportation. If the service isn't in their community, they can't access it."

<u>Theme 3</u>: Caregivers need for early intervention and care planning supports

CDG participants expressed that caregivers require early guidance and proactive planning because many are ill-prepared when their loved one first receives a diagnosis. This highlights the need for raising awareness about, and linking caregivers to, appropriate resources (based on the ADRD diagnosis and stage) as early as possible. Caregivers should be equipped with "the right tools at the moment of diagnosis," which will help them reduce stress and build long-term support as conditions progress and situations change.

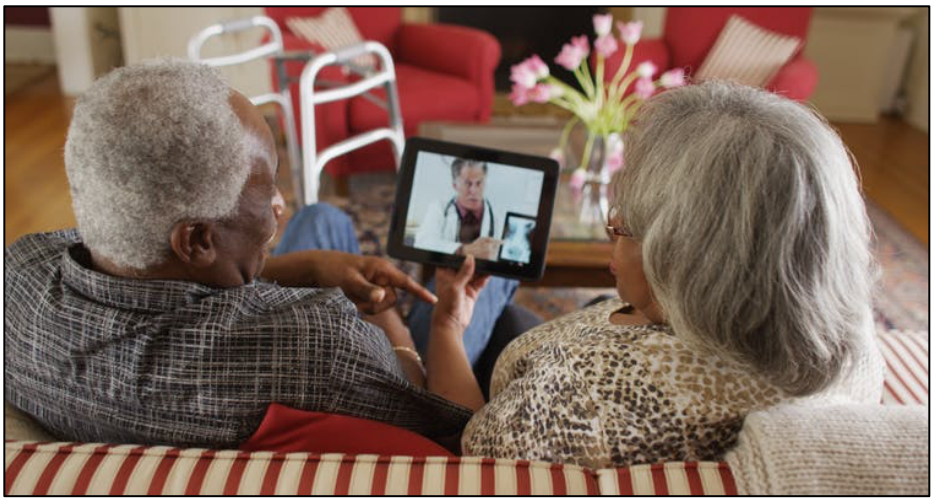
- "If caregivers were provided with resources at the time of diagnosis, they could manage better over time."

- “Just everything being a little bit earlier... We can predict some needs at time of diagnosis.
- “I think just getting the word out... people will say to me, ‘Where were you 6 months ago?’ I say, ‘I’ve been here.’”
- "Doctors’ offices need to be educated so they can refer caregivers properly."

<u>Theme 4</u>: Technological barriers

CDG participants expressed that many resources for caregivers are being delivered electronically or in the virtual space. This raises an issue for those with low digital literacy or those impacted by the “digital divide.” Participants expressed that some older caregivers they work with lack the digital literacy and technological skills to navigate available resources. These barriers are compounded in rural communities where virtual resources are less accessible. CDG participants stressed the value and benefits of telehealth, especially given caregivers’ needs to remain with their care recipient and the burden for service providers to travel long distances to see clients in geographically dispersed service areas. Although telehealth is seen as a strong opportunity for caregiving services, it is only valuable for those who can access it effectively. Participants expressed that technological literacy programs and a stronger digital infrastructure are needed in Texas.

- "A lot of our people are not computer literate… they don't have anyone to fill out information for them."
- “We’ve pushed tech solutions, but we’ve found that many caregivers don’t have the time or energy to learn how to use them, even if they are potentially helpful.”
- “We should find ways to use technology to improve processes. Sometimes our organization's processes are antiquated, and they're not keeping up with the demand. They're not keeping up with where we are in society and where we are with the need. And, so sometimes reviewing those processes and finding ways to use technology, or finding ways to improve those processes, can move things along a little bit quicker or let us do more with less.”
- “Telehealth has been a lifesaver for rural caregivers. They don’t have to drive hours to see a therapist or doctor anymore. But it still needs work to be fully effective, especially when caregivers aren’t tech-savvy.”



- "Many people shy away from online support groups and educating themselves about the disease."

Theme 5: Cultural and linguistic barriers

CDG participants expressed that cultural and language differences among caregivers in their service area can lead to an underutilization of caregiving services and resources. Participants expressed that these types of barriers can impact caregivers' trust with service providers and their ability to engage with available resources. For example, in Hispanic/Latino communities, there may be a cultural reluctance to seek external help from organizations because of language and cultural stigma (e.g., not being seen as strong or able to handle familial responsibilities). Caregivers may be reluctant to use services and resources they feel are not designed for them. Participants expressed that multilingual and culturally appropriate outreach is important, especially when attempting to reach underserved populations. Participants also expressed the value of "culturally sensitive programs" and the use of community health workers, who are more likely to speak the caregivers' preferred languages and are familiar with their culture.

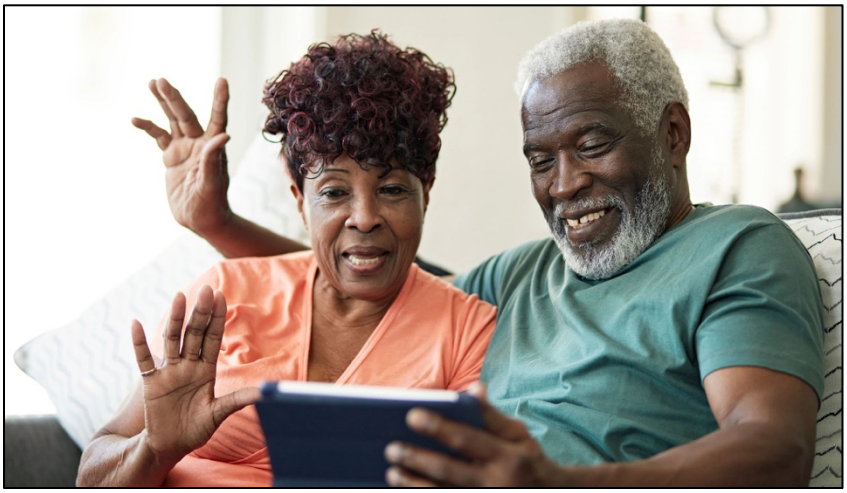
- "Language is a huge barrier. Many caregivers feel they can't reach out for help because they're afraid of being misunderstood, or worse, feeling dismissed."
- "We do have things in Spanish... we have one Spanish-speaking person, but we try... if we know in advance, we can try to get someone to help us."
- "In the Hispanic community, there's a sense of pride in taking care of family and seeking outside help can sometimes feel like an admission of failure. It's a cultural stigma."
- "Maybe the caregiver doesn't speak English. Maybe their culture says you don't go to these types of things. Maybe they don't trust the establishment or the medical community."

Theme 6: Shortages of geriatric specialists and the ADRD service workforce

CDG participants expressed that caregivers have barriers accessing services, in part, because there are shortages in clinical specialists and services providers. This is especially true in rural communities where staffing shortages can limit the volume and quality of available caregiving services. Workforce shortages create long waitlists (and potentially long travel distances) to get appointments and access services. Participants expressed that, because of these barriers, caregivers can start to feel isolated or disconnected from the services they need, which may make them reluctant to try and seek help. These barriers also make it difficult for caregivers to establish longer-term relationships between caregivers and service providers. CDG participants referenced the need to "incentivize healthcare professionals" with experience in geriatric care to position them (and keep them) in rural and underserved regions. CDG participants also suggested engaging more students to get them interested in aging and ADRD. Finally, they suggested implementing more group-level interventions to help address common caregiver concerns in a coordinated manner and alleviate service provider burdens associated with one-on-one interactions.

- “There are just not enough trained professionals to handle the scale of need. It's especially hard in rural areas. A lot of the caregiving workforce is underpaid, which results in high turnover.”
- "We need more workers in the community. So much has gone virtual; we need in-person help."
- "The community takes care of its residents to the best of its ability, but there’s a lack of funding and physical support."
- "Services need to be provided more quickly and efficiently. The waiting lists are too long, and the person may pass away before services are even provided."
- “We need incentives to encourage professionals to work in these areas—whether it’s loan repayment, financial bonuses, or even making housing more affordable. If we can draw in skilled workers, it can really help with the shortage.”
- “I think the more that you can get students involved early on, who are exploring where they want their career to go, or interested at all, the better it could be to show how versatile this field can be in all the different areas of need that we can help to attend to.”
- “They can do like a 1-stop shop and get everything while they're there. Get someone to do the screening tools, you know, and if they are on the higher end of needing assistance, then you know, they go to the FQHC where they can go in and qualify for reduced rates and just have everything right there at their doctor's office. So that and somebody there can help them navigate the system because a lot of times it's about navigating the system, and you just get fed up when you hit roadblocks, the stumbling blocks. If they're already in the system at their doctor's offices, or whatever, all the information can just transfer on down the line, and you could get people to just help them navigate.”

SUMMARY OF FINDINGS



Two statewide surveys and four community discussion groups (CDG) were conducted in 2025 to better understand the needs of ADRD caregivers and the organizations that support them in Texas. About 580 caregivers and 50 organizations responded to the surveys, representing both urban and rural regions of the state. Twenty-nine representatives of community organizations participated in CDG to offer additional in-depth insights and confirm survey findings. Caregivers shared personal experiences about their service needs and challenges of caregiving. Organizations described the services they provide, the systemic barriers they face, and their beliefs about caregiving-related barriers. Together, the surveys and CDG provide a glimpse into caregiver service gaps, obstacles to accessing caregiver resources, and opportunities for improving ADRD caregiving support in Texas.

Caregivers most often reported needing but not using services such as caregiving technologies, dementia research updates, health and wellness programs, respite care, and transportation. These needs were especially pronounced in rural areas, where caregivers reported more limited availability and accessibility of services. Organizations confirmed many of these gaps reported by caregivers. Organizations reported that most organizations offer community services and end-of-life planning, but far fewer provide technologies, financial or legal planning, transportation, or respite care. Caregivers and organizations both identified the same categories of services as under-provided. However, caregivers stressed day-to-day needs like health and wellness and respite care, while organizations highlighted gaps in structural supports like financial and legal planning.

Awareness and access were central issues for caregivers and organizations. Caregivers reported low awareness about community resources, had difficulties accessing services, and believed that too few services existed in their area. Organizations largely agreed with caregiver reports, but organizations were more likely to describe services as available in their service areas. These discrepancies suggest a disconnect between what services organizations believe to exist and what services caregivers are actually able to use. Similarly, caregivers and organizations both believed accessibility is especially challenging in rural areas, where distance, transportation costs, and limited internet access compound service inaccessibility.

Caregivers and organizations described barriers to service access and use in complementary ways. Caregivers reported information gaps, financial strain, and appointment delays as the biggest obstacles, while organizations emphasized workforce shortages, long waitlists, and infrastructure issues. Organizations reported that caregivers in certain groups (e.g., older, rural residing, Hispanic/Latino, lower income, disabled) were disproportionately encountered barriers to caregiving service access and use. CDG added further depth to these survey findings, highlighting the need to recognize and address caregiver burnout, cultural and language barriers, the need for early guidance at diagnosis, and challenges with digital literacy and telehealth access.

Despite the range of challenges reported, caregivers and organizations had strong agreement about what should be prioritized to support ADRD care in their areas. Caregivers and organizations both identified the same top three actions priorities, which included raising awareness about resources, improving accessibility of services, and training healthcare providers to better support ADRD caregivers and families living with dementia.

Findings from this needs assessment underscore the need to address both personal and systemic barriers. Addressing these barriers can support the health and service utilization of ADRD caregivers, while strengthening the ADRD service infrastructure and expanding the ADRD service workforce in Texas.

RECOMMENDATIONS FOR THE SUSTAINABILITY OF ADRD-RELATED ACTIVITIES

The data collected during this needs assessment point to practical and actionable opportunities to improve ADRD-related service availability, access, and use in Texas. A series of recommendations were generated based on the reported needs, barriers, and priorities identified by caregivers and organizations in the surveys and CDG. Many of these recommended strategies can be initiated quickly to improve awareness and service access, while others may take a bit more time to build capacity and transform systems in Texas.

- Enhance outreach and awareness
    - Launch statewide and local awareness campaigns (explain services, eligibility, how to access)
    - Collaborate with trusted, local leaders and entities
    - Implement targeted and tailored outreach in rural and underserved areas
    - Provide informational kits to share with caregivers at the time of ADRD diagnosis (local resources, contacts, planning tools)
    - Offer workshops about future care planning (e.g., legal, financial, housing, treatment) to help families prepare
    - Bridge the disconnect between caregiver and organizational perspectives on service availability, accessibility, and adequacy

- Simplify service access and increase care navigation
    - Hire and station care navigators in priority locations with high ADRD burden
    - Station navigators in priority locations
    - Streamline eligibility/application, service delivery, and referral processes
    - Simplify materials and information delivery
    - Create caregiver feedback mechanisms to improve clinical and community processes
    - Create centralized, co-located service hubs to reduce travel and time costs
    - Expand transportation supports (vouchers, ride programs, volunteer-driven)

- Expand support for caregiver self-care, health, and well-being
    - Reinforce that caregivers must protect themselves to be effective caregivers
    - Innovate caregiver respite programs
    - Promote the use of peer-led caregiver support groups
    - Introduce and pilot new wellness programs, offered in-person and/or virtually
    - Integrate mental health services and resources into caregiving programs
    - Integrate screenings into primary care visits to identify risk factors (stress, depression, social disconnection) and refer high risk individuals to support services
    - Promote subsidies, stipends, and tax credits for unpaid caregivers

    - Expand financial/legal counseling and planning services statewide
    - Support low-cost/subsidized respite and wellness programs

- Increase the availability of geriatric specialists and the ADRD service providers
    - Incentivize practitioners and service providers in rural and underserved areas (e.g., loan repayment, stipends, housing support)
    - Recruit and train more respite care providers, aides, and dementia specialists
    - Expand telehealth services, while implementing additional measures to account for digital literacy and the "digital divide"
    - Develop training programs on ADRD for community health workers and *promotoras*
    - Innovate community-clinical referral pathways and/or training programs for healthcare providers to make early referrals to services when ADRD is first diagnosed
    - Implement ADRD training and placement programs for medical students and volunteers, with additional incentives for placement in high-need areas)
    - Develop and deliver group-based interventions for caregivers to alleviate strain on limited staff while meeting need

- Address cultural and language barriers
    - Build partnerships with trusted community leaders and organizations to facilitate outreach and service access
    - Incorporate culturally appropriate context into materials and services
    - Provide multicultural materials and services (incorporating bilingual staff and volunteers)
    - Normalize the utilization of caregiving services and supports
    - Engage community health workers and *promotoras*

- Enhance telehealth and virtual support
    - Expand broadband access in rural and underserved areas
    - Expand telehealth programs for caregiver support
    - Provide caregiver training about technology and digital literacy
    - Increase awareness of and access to technology for caregiving support
    - Expand online support networks (and/or hybrid models to accommodate what works best for caregivers)
    - Harmonize cross-sectoral online systems for service delivery, referrals, etc., to reduce redundancy and improve engagement timeliness

Given the complexity of ADRD caregiving service needs amidst the growing number of ADRD caregivers in Texas, these recommendations can be thought of in terms of short-, medium-, and long-term actions. The below graphic depicts these recommendations based on the temporality of action.

Short-Term Quick Wins

Raise Awareness
- Launch and expand community awareness campaigns in plain language (radio, clinics, social media)

Navigate
- Station navigators in priority locations
- Provide informational kits to share with caregivers at the time of ADRD diagnosis (local resources, contacts, planning tools)

Focus on Caregiver Health
- Screen caregivers for stress, depression, burnout) during routine care visits
- Introduce and pilot new wellness programs (virtual and in-person)

Transportation
- Introduce voucher or volunteer driver programs in rural-underserved areas

Medium-Term Build Capacity

Service Expansion
- Scale respite care (e.g., in-home, adult day services, volunteer-based)
- Establish co-located service hubs and bundle virtual services
- Expand digital literacy programming

Workforce Development
- Incentivize professionals to work in rural/under-served areas (e.g., stipends, loan repayment)
- Enhance training for community health workers and *promotoras*
- Develop student training and volunteer pipelines for respite and dementia care

Tailor for Expansion
- Establish multi-lingual hotlines, programs, and resources
- Launch targeted outreach strategies

Long-Term System Transformation

System Sustainability
- Support advisory councils to guide policy and track progress
- Create harmonized online systems for service referral, navigation, and data sharing

Financial Supports
- Promote subsidies, stipends, and tax credits for unpaid caregivers
- Expand financial/legal counseling services statewide
- Support low-cost/subsidized respite and wellness programs

Technology Infrastructure
- Expand broadband in rural areas
- Promote hybrid service delivery

APPENDICES

Appendix A.
Survey 1: Unpaid Caregivers

Eligibility: You are invited to participate in this survey if you provided unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementias (ADRD) in the past 6 months. To be eligible to participate in this survey, you and/or care recipient must have lived in Texas in the past 12 months.

For this survey, a "caregiver" refers to the person who provides unpaid care or assistance to a relative or friend with ADRD. Some people identify with the term "caregiver," while others do not. This term and other terms are defined below. Only continue with the survey if you describe yourself as a "caregiver" to the care recipient.

Definitions:

- **Care recipient** refers to the person with Alzheimer's disease or other dementia who receives/received care or assistance.
- **Caregiver** refers to the person who provides/provided care or assistance to a relative or friend with Alzheimer's disease or other dementias.
- **Health care provider** refers to any professional who provides health care services, such as doctors, nurses, mental health professionals, and dentists.
- **Respite care** refers to a short-term break from caregiving responsibilities. The intent of respite care is for others to take over caregiving responsibilities so that caregivers may receive temporary support to rest and recharge so they can continue to provide care.
- **Alzheimer's disease or other dementias (ADRD)** refers to Alzheimer's disease or other dementias and other forms of dementia such as Lewy body disease, vascular dementia, or frontotemporal dementia.

INCLUSION

In the past 6 months, have you provided unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementias (ADRD)?

- Yes, I currently provide unpaid care or assistance
- Yes, I provided unpaid care or assistance in the past 6 months, but I do not currently
- No (End survey)

In the past 12 months, have you and/or your care recipient lived in Texas?

- Yes
- No (End survey)

CAREGIVER

What is your age?

- Under 18 years old
- 18 - 24 years
- 25 - 34 years
- 35 - 44 years
- 45 - 54 years
- 55 - 64 years
- 65 - 74 years
- 75 - 84 years
- 85 years or older

What is your gender?

- Female
- Male
- Non-binary
- I prefer to self-describe

Are you of Hispanic, Latino, or Spanish origin?

- No
- Yes
- I prefer to self-describe

Which of the following groups would you say best represents your race? (select all that apply)

- White
- Black or African American
- Native American or American Indian
- Asian/ Pacific Islander
- I prefer to self-describe (please specify)

What is the highest level of education you have completed?

- Less than high school diploma
- High school graduate
- Vocational/trade/technical school
- Some college
- Bachelor’s degree
- Advanced degree

What is your current relationship status?

- Married or Partnered
- Widowed
- Divorced
- Separated
- Never Married

What is your current employment status?

- Employed full-time
- Employed part-time
- Unemployed/Looking for work
- Unemployed/Not looking for work
- Student
- Retired

What is the 5-digit ZIP Code where you live? _____

In what language do you speak at home?

- English
- Spanish
- Another language (please specify)_____

In what language do you prefer to get health-related information?

- English
- Spanish
- Another language (please specify)_____

Do you have a ride or the transportation you need to get where you want to go?

- Yes
- No

Do you own a smartphone, computer, laptop, or tablet?

- Yes
- No

Are you worried or stressed about having enough money to meet your basic needs?

- Yes
- No

CARE RECIPIENT & CAREGIVING SITUATION

What is your care recipient's age? [drop down]

- Under 18 years old
- 18 - 24 years
- 25 - 34 years
- 35 - 44 years
- 45 - 54 years
- 55 - 64 years
- 65 - 74 years
- 75 - 84 years
- 85 years or older

What is your care recipient's gender?

- Female
- Male
- Non-binary
- I prefer to self-describe

Is your care recipient of Hispanic, Latino, or Spanish origin?

- No
- Yes
- I prefer to self-describe

Which of the following groups would you say best represents your care recipient's race? (select all that apply)

- White
- Black or African American
- Native American or American Indian
- Asian/ Pacific Islander
- I prefer to self-describe (please specify)

What is the highest level of education your care recipient has completed?

- Less than high school diploma
- High school graduate
- Vocational/trade/technical school
- Some college
- Bachelor's degree
- Advanced degree

What is the 5-digit ZIP Code where your care recipient lives? _____

Which of the following best describes your care recipient’s dementia diagnosis? (select all that apply)

- Alzheimer’s disease
- Vascular dementia
- Lewy body disease
- Frontotemporal dementia
- Parkinson’s disease
- Mixed dementia
- Another type of dementia
- Mild cognitive impairment
- I don’t know

Approximately how long ago was your care recipient told by a health care provider that they had dementia? _____months _____years

Approximately how long ago did you first notice that your care recipient had memory problems or signs of dementia? _____months _____years

How would you describe the stage of your care recipient’s dementia?

- Mild stage of dementia (i.e., still functions independent, but may experience memory lapses like forgetting familiar words or locations)
- Moderate stage of dementia (i.e., more pronounced memory symptoms like confusing words, getting frustrated or angry, and acting in unexpected ways)
- Severe stage of dementia (i.e., loss of ability to respond to their environment, carry on conversations, or control movements)

What is the care recipient's relationship to you?

- Grandmother
- Grandfather
- Mother
- Mother-in-law (or mother of partner, if not married)
- Father
- Father-in-law (or father of partner, if not married)
- Spouse/partner
- Sibling
- Daughter
- Son
- Non-relative
- Other (please specify)

Do you live with your care recipient?

- Yes (skip to next question)
- No

If yes, how many individuals reside in your household (including yourself and your care recipient)?

- 2 people (only us)
- 3 people
- 4 people
- 5 or more people

Including yourself, how many people provide unpaid care or assistance to the care recipient?

- 1 person (me)
- 2 people
- 3 people
- 4 people
- 5 or more people
- I don’t know

Do you consider yourself to be the person who provides most of the unpaid care or assistance to the care recipient?

- Yes
- No

Does someone else provide paid care or assistance to the care recipient?

- Yes
- No
- I don’t know

Which of the following tasks do you regularly help the care recipient with? Select all that apply.

- Activities of daily living (e.g., dressing, bathing, toileting, eating)
- Transportation
- Housework
- Grocery shopping
- Managing finances/paying the bills
- Preparing meals
- Helping with medication
- Managing visits with health care providers (e.g., scheduling appointments, talking to the doctor)
- Providing companionship
- Providing supervision to protect the care recipient
- Other (please specify)_____

About how many hours in a typical week do you provide unpaid care or assistance to your care recipient with ADRD? [Answer by moving the slider with your mouse or by clicking on the slider and dragging it.]

- Range from 0 - 168 hours per week

SERVICE AND RESOURCE USE

When thinking about your role as a caregiver over the past 6 months, please describe your need for, and use of, the following services and resources.

	Did Not Need	Needed, But Did Not Use	Needed and Used
Guidance about diagnosis and disease symptoms	1	2	3
Guidance about treatment and care	1	2	3
Care planning for disease transitions	1	2	3
Financial planning	1	2	3
Legal planning	1	2	3
Respite care (i.e., short-term break from caregiving responsibilities)	1	2	3
Community resources (e.g., classes, support groups, local Alzheimer's-related nonprofits)	1	2	3
Health and wellness programs	1	2	3
Transition to long-term care facilities (e.g., nursing homes, assisted living facilities)	1	2	3
Learning about opportunities for ADRD treatments in development (e.g., clinical trials)	1	2	3
Information about how to remain safe as a caregiver (e.g., methods for preventing and managing aggressive conflicts)	1	2	3
Information about safely providing care to recipients (e.g., safe storage of medication, wander prevention methods)	1	2	3

	Did Not Need	Needed, But Did Not Use	Needed and Used
Prevention of abuse, neglect, and exploitation of care recipient	1	2	3
Transportation issues and driving concerns	1	2	3
Grief and loss (e.g., loss of care recipient, changing role as a daughter, son, spouse)	1	2	3
End-of life planning (e.g., palliative care, hospice)	1	2	3
Learning about the newest research about cognitive impairment (e.g., causes, services, treatments)	1	2	3
Learning about helpful technologies for caregiving (e.g., apps, platforms, devices)	1	2	3

When thinking about the area you live in, please describe if the following services and resources are available and easy to access?

	Not Available	Available and Easy to Get To	Available But NOT Easy To Get To	I Don't Know
Information about diagnosis and disease symptoms	1	2	3	4
Information about treatment and care	1	2	3	4
Care planning for disease transitions	1	2	3	4
Financial planning	1	2	3	4

	Not Available	Available and Easy to Get To	Available But NOT Easy To Get To	I Don't Know
Legal planning	1	2	3	4
Respite care	1	2	3	4
Community resources	1	2	3	4
Health and wellness programs	1	2	3	4
Information about transitions to long-term care facilities	1	2	3	4
Information about ADRD treatments in development	1	2	3	4
Information about how to remain safe as a caregiver	1	2	3	4
Information about safely providing care to recipients	1	2	3	4
Information about prevention of abuse, neglect, and exploitation of care recipient	1	2	3	4
Transportation services	1	2	3	4
Information about grief and loss	1	2	3	4
End-of life planning	1	2	3	4
Research about cognitive impairment	1	2	3	4
Technologies for caregiving	1	2	3	4

Many things can get in the way of caring for your care recipient. Please describe your level of agreement with each of the following statements.

	Strongly Disagree	Disagree	Agree	Strongly Agree
I need help learning what I should be doing to take better care of my care recipient	1	2	3	4
I need help learning how to take better care of my care recipient in a way that works for me and my life	1	2	3	4
I don't have the money it takes to give the best care to my care recipient	1	2	3	4
My health problems and conditions make it difficult for me to care for my care recipient	1	2	3	4

Other than cost, have any of the following delayed you from getting caregiving services you needed in the past 6 months?

	No	Yes
I didn't know who to call for what I needed	1	2
I couldn't get through on the telephone	1	2
I couldn't get an appointment soon enough	1	2
The office wasn't open when it was convenient for my schedule	1	2
I didn't have transportation	1	2

To what degree do the following statements describe the community you live in?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
I am aware of the community resources that can help support me care for my care recipient	1	2	3	4	5
There are enough community resources where I live that can help support me care for my care recipient	1	2	3	4	5
The community services where I live are accessible to people with ADRD and their	1	2	3	4	5

To what degree do you believe the following statements should be a priority for action in your community?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Raising awareness about resources that can help support people with dementia and their families	1	2	3	4	5
Creating dementia-related resources tailored to our diverse and underserved populations	1	2	3	4	5
Making services in our community more accessible to people with ADRD and their caregivers	1	2	3	4	5
Providing training for health care providers about how to best support caregivers and people with ADRD	1	2	3	4	5

ADDITIONAL CAREGIVER INFORMATION

How often do you feel you get the help and support you need to:	Never	Rarely	Occasionally	Frequently	Always
Care for your care recipient?	1	2	3	4	5
Manage your own health?	1	2	3	4	5

How would you describe your current social support system?
- Poor
- Fair
- Good
- Very Good
- Excellent

In general, would you say your health is:
- Poor
- Fair
- Good
- Very Good
- Excellent

Think about your **physical health**, which includes physical illness and injury. For how many days **during the past 30 days** was your physical health **not good**?
_____ days

Think about your **mental health**, which includes stress, depression, and problems with emotions. For how many days **during the past 30 days** was your mental health **not good**?
_____ days

During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?
_____ days

On a scale from 1 (Not At All) to 10 (A Great Deal), how has providing care or assistance to your care recipient negatively affected your:
- Physical health
- Mental health
- Sleep
- Ability to manage your own health
- Ability to socialize with others
- Finances

Appendix B.

Survey 2: Organizations Serving Caregivers

Eligibility: You are invited to participate in this survey if your organization provides programs, services, or resources to unpaid caregivers of individuals with Alzheimer's disease or other dementias (ADRD). To be eligible to participate in this survey, your organization must conduct business in Texas and serve Texas residents.

For this survey, a "caregiver" refers to the person who provides unpaid care or assistance to a relative or friend with ADRD. Some people identify with the term "caregiver," while others do not. This term and other terms are defined below. Only continue with the survey if you describe that your organization serves "caregivers" of individuals with ADRD.

Definitions:

- **Care recipient** refers to the person with Alzheimer's disease or other dementia who receives/received care or assistance.
- **Caregiver** refers to the person who provides/provided care or assistance to a relative or friend with Alzheimer's disease or other dementias.
- **Health care provider** refers to any professional who provides health care services, such as doctors, nurses, mental health professionals, and dentists.
- **Respite care** refers to a short-term break from caregiving responsibilities. The intent of respite care is for others to take over caregiving responsibilities so that caregivers may receive temporary support to rest and recharge so they can continue to provide care.
- **Alzheimer's disease or other dementias (ADRD)** refers to Alzheimer's disease or other dementias and other forms of dementia such as Lewy body disease, vascular dementia, or frontotemporal dementia.

Organization refers to an entity engaged in commercial, industrial, or professional activities to serve or support caregivers of people with ADRD. Organizations can include for-profit or non-profit organizations.
Service area refers to the geographical region where an organization actively provides its services to caregivers of people with ADRD. This could include a single city, a single county, or a wider area.

INCLUSION

Does your organization serve unpaid caregivers of people with ADRD in the State of Texas?
a. Yes
b. No (End survey)

ABOUT YOUR ORGANIZATION

Please tell us about the organization you work for:

- What is your organization's name?
- What is the primary address? (city, county, ZIP only)

How would you describe your organization? (select all that apply):

- State Unit on Aging
- Library
- Municipal Government
- Multi-purpose Social Services Organization
- Area Agency on Aging
- Recreational Organization
- State Health Department
- Residential Facility
- County Health Department
- Senior Center
- Educational Institution
- Other Community Center
- Faith-based Organization
- Tribal Center
- Health Care Organization
- Other (please specify):

Approximately how many total people are employed by your organization?

- 1 to 25 people
- 26 to 50 people
- 51 to 100 people
- 101 or more people

Please describe your service area.

- In how many Texas counties do you serve caregivers of individuals with ADRD?

Please describe the caregivers you serve.

- Approximately what percent (%) of your services are specific to unpaid caregivers of individuals with ADRD? _____
- Approximately what percent (%) of the caregivers you serve:
  - Are ages 60 years and older? _____
  - Have a disability? _____
  - Reside in rural areas? _____
  - Are female? _____
  - Are Hispanic/Latino? _____
  - Are Black or African American? _____
  - Are Native American or American Indian? _____
  - Are Asian/ Pacific Islander? _____
  - Are Impoverished? _____

Approximately what proportion of caregivers of individuals with ADRD have care recipients with the following dementia diagnoses?

- Alzheimer's disease (%, DK)
- Vascular dementia (%, DK)
- Lewy body disease (%, DK)
- Frontotemporal dementia (%, DK)
- Parkinson's disease (%, DK)
- Mixed dementia (%, DK)
- Another type of dementia (%, DK)
- Mild cognitive impairment (%, DK)

ABOUT YOU

What is your job title? _____

About how many years have you worked for your organization? _____

About how many years have your worked in your current position? _____

Which most accurately describes your current employment situation?

- Full-time permanent employee
- Full-time temporary employee
- Part-time permanent employee
- Part-time temporary employee
- I don't work for the organization (e.g., volunteer)

What is your age?

- Under 18 years old
- 18 - 24 years
- 25 - 34 years
- 35 - 44 years
- 45 - 54 years
- 55 - 64 years
- 65 - 74 years
- 75 - 84 years
- 85 years or older

What is your gender?

- Female
- Male
- Non-binary
- I prefer to self-describe

Are you of Hispanic, Latino, or Spanish origin?

- No
- Yes
- I prefer to self-describe

Which of the following groups would you say best represents your race/ethnicity? (select all that apply)

- White, non-Hispanic
- Black or African American
- Native American or American Indian
- Asian/ Pacific Islander
- I prefer to self-describe (please specify)

What is the highest level of education you have completed?

- Less than high school diploma
- High school graduate
- Vocational/trade/technical school
- Some college
- Bachelor's degree
- Advanced degree

Do you have any of the following credentials or certifications? (select all that apply)

- Certified Dementia Practitioner (CDP)
- Certified Dementia Care Manager
- Certified Dementia Care Specialist
- Certified Alzheimer's Disease and Dementia Care Trainer (CADDCT)
- Certified Montessori Dementia Care Professional (CMDCP)
- essentiALZ Certification
- Community Health Worker or Promotora
- Other (please specify)

SERVICE AND RESOURCE USE

When thinking about the services your organization provides to caregivers, which of the following does your organization provide?

	We Do Not Provide	We Provide	I Don't Know
Information about diagnosis and ADRD symptoms	1	2	3
Information about treatment and care	1	2	3
Care planning for disease transitions	1	2	3

	We Do Not Provide	We Provide	I Don't Know
Financial planning	1	2	3
Legal planning	1	2	3
Respite care	1	2	3
Community resources	1	2	3
Health and wellness programs	1	2	3
Information about transitions to long-term care facilities	1	2	3
Information about ADRD treatments in development	1	2	3
Information about how to remain safe as a caregiver	1	2	3
Information about safely providing care to recipients	1	2	3
Information about prevention of abuse, neglect, and exploitation of care recipient	1	2	3
Transportation services	1	2	3
Information about grief and loss	1	2	3
End-of life planning	1	2	3
Research about cognitive impairment	1	2	3
Technologies for caregiving	1	2	3

When thinking about your organization's service area, please describe if the following services and resources are available and easy to access for caregivers of individuals with ADRD.

	Not Available	Available and Easy to Get To	Available But NOT Easy To Get To	I Don't Know
Information about diagnosis and disease symptoms	1	2	3	4
Information about treatment and care	1	2	3	4
Care planning for disease transitions	1	2	3	4
Financial planning	1	2	3	4
Legal planning	1	2	3	4
Respite care	1	2	3	4
Community resources	1	2	3	4
Health and wellness programs	1	2	3	4
Information about transitions to long-term care facilities	1	2	3	4
Information about ADRD treatments in development	1	2	3	4
Information about how to remain safe as a caregiver	1	2	3	4
Information about safely providing care to recipients	1	2	3	4
Information about prevention of abuse, neglect, and exploitation of care recipient	1	2	3	4
Transportation services	1	2	3	4

	Not Available	Available and Easy to Get To	Available But NOT Easy To Get To	I Don't Know
Information about grief and loss	1	2	3	4
End-of life planning	1	2	3	4
Research about cognitive impairment	1	2	3	4
Technologies for caregiving	1	2	3	4

How do you believe the caregiving services in your organization's service area have changed over the past five years?

- Greatly improved
- Improved
- No change
- Worsened
- Greatly worsened

BARRIERS TO SERVICE UTILIZATION

Many things can get in the way of caring for a care recipient with ADRD. To what degree do the following barriers for caregivers affect their access to caregiving services in your organization's service area?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Financial barriers	1	2	3	4	5
Insufficient insurance coverage	1	2	3	4	5
Transportation barriers	1	2	3	4	5
Geographical barriers (e.g., rural residence)	1	2	3	4	5
Low health literacy	1	2	3	4	5
Language barriers	1	2	3	4	5

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Cultural barriers	1	2	3	4	5
Lack of social supports	1	2	3	4	5
Lack of knowledge and awareness about resources	1	2	3	4	5
Difficulty navigating complex care systems	1	2	3	4	5
Eligibility restrictions for services	1	2	3	4	5

To what degree do the following describe barriers to accessing services in your organization's service area?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Not enough organizations serving caregivers	1	2	3	4	5
Workforce shortages	1	2	3	4	5
Location of service organizations	1	2	3	4	5
Limited appointment availability (e.g., operation hours)	1	2	3	4	5
Long waitlist for services	1	2	3	4	5
Inadequate access to high-speed internet	1	2	3	4	5

[SKIP PATTERN for MODERATE+] When thinking about the barriers identified above, to what degree do these barriers disproportionately impact the following caregiver groups?

- Ages 60 years and older?
- Have a disability?
- Reside in rural areas?
- Women?
- Hispanic/Latino?
- Black or African American?
- Native American or American Indian?
- Asian/ Pacific Islander?
- Impoverished?

To what degree do the following statements describe barriers to accessing services in your organization's service area?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Caregivers need help learning what they should be doing to take better care of their care recipient.	1	2	3	4	5
Caregivers need help learning how to take better care of their care recipient in a way that works for them and their life.	1	2	3	4	5
Caregivers don't have the money it takes to give the best care to their care recipient.	1	2	3	4	5
Caregivers' health problems and conditions make it difficult for them to care for their care recipient.	1	2	3	4	5

COMMUNITY PERCEPTIONS

To what degree would you agree with the following statements?

	Strongly Disagree	Disagree	Agree	Strongly Agree
Caregivers' needs are being met by the services and programs provided in my service area.	1	2	3	4
Caregivers are aware of the services and programs provided by my organization.	1	2	3	4
My organization adequately meets the needs of caregivers of individuals with ADRD.	1	2	3	4
Organizations in our service area routinely partner to offer services to caregivers of individuals with ADRD.	1	2	3	4
Organizations in our service area routinely refer caregivers of individuals with ADRD to one another for services.	1	2	3	4

To what degree do the following statements describe your organization's service area?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Caregivers are aware of the community resources that can help support them care for their care recipient.	1	2	3	4	5
There are enough community resources that can help support caregivers care for their care recipient.	1	2	3	4	5
The community services are accessible to people with ADRD and their caregivers.	1	2	3	4	5

To what degree do you believe the following statements should be a priority for action in your organization's service area?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Raising awareness about resources that can help support people with dementia and their families.	1	2	3	4	5
Creating dementia-related resources tailored to our diverse and underserved populations.	1	2	3	4	5
Making services in our community more accessible to people with ADRD and their caregivers.	1	2	3	4	5
Providing training for health care providers about how to best support caregivers and people with ADRD	1	2	3	4	5

OPPORTUNITIES

When thinking about your organization's service area, to what degree do you believe the following would increase support to unpaid caregivers of individuals with ADRD?

	Not At All	A Little	A Moderate Amount	A Lot	A Great Deal
Increased outreach and education	1	2	3	4	5
Streamlining application processes for services	1	2	3	4	5
Increased financial assistance programs	1	2	3	4	5
More caregiver support programs	1	2	3	4	5
Strengthened community partnerships	1	2	3	4	5
Flexible service options	1	2	3	4	5
More state/federal funds dedicated to caregiver supports	1	2	3	4	5
Availability of technological solutions	1	2	3	4	5
Availability of trained professionals	1	2	3	4	5

OPEN ENDED

What are the main strengths for addressing the needs of caregivers of individuals with ADRD in your organization's service area?

What are the main gaps for addressing the needs of caregivers of individuals with ADRD in your organization's service area?

What resources are needed in your organization's service area to address the needs of caregivers of individuals with ADRD?

APPENDIX C.

Findings from a Statewide Needs Assessment

Texas ranks in the top five highest states of Alzheimer's Disease and related dementias (ADRD) cases. It is estimated that caregivers in Texas provide an estimated 1.9 million hours of unpaid care each year.

Two statewide surveys and four community discussion groups were conducted to better understand the needs of ADRD caregivers and the organizations that support them.

	Unpaid ADRD Caregivers	Organizations Serving Caregivers
Unmet Needs & Service Provision	Largest Unmet Needs: • Learning about new technologies for caregiving • Learning about the newest research about cognitive impairment • Learning about opportunities for ADRD treatments in development • Health and wellness programs • Community resources • Respite care	Least Provided Services: • Technologies for caregiving • Financial planning • Legal planning • Research about cognitive impairment • Information about ADRD treatments in development • Transportation services • Respite care
Awareness & Adequacy	• Self-report low awareness about services • Believe services are insufficient and not always accessible	• Report caregivers have low awareness about services • Believe services are insufficient and not always accessible

Caregivers and organizations identified deficits in respite care and technology, research, and respite care.

Caregivers and organizations agree caregiver awareness is low, resources are lacking, and accessibility is limited

	Unpaid ADRD Caregivers	Organizations Serving Caregivers
Availability & Accessibility	Most Unavailable Services: • information about ADRD treatments in development • Technologies for caregiving • Transportation services • Community resources Many caregivers reported services/resources were available, but difficult to access.	Most Unavailable Services: • Transportation services • Technologies for caregiving • Research about cognitive impairment • Legal planning Many organizations believed services/ resources were available at higher rates and largely accessible to caregivers.
Barriers to Getting Services	• Not knowing who to call • Appointment delays • Limited financial resources	• Long waitlists • Workforce shortages • Inadequate internet • Location of services • Disproportionate barriers for certain caregiver groups
Action Priorities	• Train healthcare providers • Raise awareness about resources • Improve accessibility	• Improve accessibility • Train healthcare providers • Raise awareness about resources

Caregivers perceive fewer available services/ resources in their areas. When available, many report they are difficult to access.

Caregivers and organizations identified financial strains and needs for guidance as barriers.

Caregivers and organizations shared the same 3 priorities.

Recommended strategies to improve ADRD-related service availability, access, and use in Texas:

- **Enhance outreach and awareness**
- **Simplify service access and increase care navigation**
- **Expand support for caregiver self-care, health, and well-being**
- **Increase the availability of geriatric specialists and the ADRD service workforce**
- **Address cultural and language barriers**
- **Enhance telehealth and virtual support**

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Appendix D.

Unmet Needs of Unpaid Dementia Caregivers in Texas

Across Texas, caregivers of people living with Alzheimer's Disease and related dementias (ADRD) often feel overwhelmed, burned out, and unsure where to turn for help.

Many caregivers cannot access the services they need, such as respite care, wellness programs, transportation, or caregiving technologies. Even when services exist, they are often difficult to reach, especially in rural areas.

Organizations that serve ADRD caregivers agree with concerns expressed by caregivers. They also identified system-level challenges like long waitlists, not enough trained workers, and difficulties reaching rural communities.

Community discussions revealed that caregivers often don't use services because they are too busy or exhausted, many families struggle with cultural or language barriers, and internet/technology challenges make it harder to connect with help. Workforce shortages and long wait times worsen the situation.

Caregivers and organizations agreed that action priorities should:

- Raise awareness about resources
- Make services easier to access
- Train healthcare providers to support caregivers and their families

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Appendix E.

Take-Aways and Priorities

Two statewide surveys and four community discussion groups were conducted to better understand the needs of ADRD caregivers and the organizations that support them.

Caregivers and organizations agree that:

- Awareness is too low among caregivers
- Service and resource availability is insufficient in many communities
- Services are not universally easy to access

Service Gaps:
Under-provided services and unmet caregiver needs surrounded technology for caregiving, respite care, transportation, financial/ legal planning, and dementia research access.

Urban vs. Rural Burden:
Rural caregivers reported less service availability across nearly all services.

Awareness:
Both caregivers and organizations reported that caregivers have low awareness about available and needed resources, which highlights the need for navigation support.

Barriers:
Caregivers reported awareness gaps, financial challenges, mental and social health needs, and appointment delays. Organizations reported more systemic barriers limiting caregiver support, such as service waitlists, workforce shortages, gaps in internet access, and geospatial and cultural obstacles.

Caregivers need support that is easy to find, culturally appropriate, affordable, and available early in the dementia journey. Organizations and policymakers can act by:

- Making services visible and simple to navigate
- Expanding respite care, health/wellness services, and transportation supports
- Training providers to support caregivers from diagnosis onward
- Investing in the workforce and infrastructure that sustain caregiving in Texas

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Appendix F.

Recommendations for Progress

Practical and actionable opportunities to improve ADRD-related service availability, access, and use in Texas.

1 Enhance outreach and awareness

- Launch statewide and local awareness campaigns (explain services, eligibility, how to access)
- Collaborate with trusted, local leaders and entities
- Implement targeted and tailored outreach in rural and underserved areas
- Provide informational kits to share with caregivers at the time of ADRD diagnosis (local resources, contacts, planning tools)
- Offer workshops about future care planning (e.g., legal, financial, housing, treatment) to help families prepare
- Bridge the disconnect between caregiver and organizational perspectives on service availability, accessibility, and adequacy

2 Simplify service access and increase care navigation

- Hire and station care navigators in priority locations with high ADRD burden
- Station navigators in priority locations
- Streamline eligibility/application, service delivery, and referral processes
- Simplify materials and information delivery
- Create caregiver feedback mechanisms to improve clinical and community processes
- Create centralized, co-located service hubs to reduce travel and time costs
- Expand transportation supports (vouchers, ride programs, volunteer-driven)

3 Expand support for caregiver self-care, health, and well-being

- Reinforce that caregivers must protect themselves to be effective caregivers
- Innovate caregiver respite programs
- Promote the use of peer-led caregiver support groups
- Introduce and pilot new wellness programs, offered in-person and/or virtually
- Integrate mental health services and resources into caregiving programs
- Integrate screenings into primary care visits to identify risk factors (stress, depression, social disconnection) and refer high risk individuals to support services
- Promote subsidies, stipends, and tax credits for unpaid caregivers
- Expand financial/legal counseling and planning services statewide
- Support low-cost/subsidized respite and wellness programs

4 Increase the availability of geriatric specialists and the ADRD service providers

- Incentivize practitioners and service providers in rural and underserved areas (e.g., loan repayment, stipends, housing support)
- Recruit and train more respite care providers, aides, and dementia specialists
- Expand telehealth services, while implementing additional measures to account for digital literacy and the "digital divide"
- Develop training programs on ADRD for community health workers and promotoras
- Innovate community-clinical referral pathways and/or training programs for healthcare providers to make early referrals to services when ADRD is first diagnosed
- Implement ADRD training and placement programs for medical students and volunteers, with additional incentives for placement in high-need areas)
- Develop and deliver group-based interventions for caregivers to alleviate strain on limited staff while meeting need

5 Address cultural and language barriers

- Build partnerships with trusted community leaders and organizations to facilitate outreach and service access
- Incorporate culturally appropriate context into materials and services
- Provide multicultural materials and services (incorporating bilingual staff and volunteers)
- Normalize the utilization of caregiving services and supports
- Engage community health workers and promotoras

6 Enhance telehealth and virtual support

- Expand broadband access in rural and underserved areas
- Expand telehealth programs for caregiver support
- Provide caregiver training about technology and digital literacy
- Increase awareness of and access to technology for caregiving support
- Expand online support networks (and/or hybrid models to accommodate what works best for caregivers)
- Harmonize cross-sectoral online systems for service delivery, referrals, etc., to reduce redundancy and improve engagement timeliness

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