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# Literature Review of Home- and Community-Based Services in Diverse Communities: Diverse Caregivers

LITERATURE REVIEW

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### **Introduction**

Long-Term Quality Alliance (LTQA) in partnership with O'Leary Marketing Associates worked with the Minnesota Department of Human Services (DHS) to explore the feasibility of programs that would assist older adults to stay in their homes as they age and their long-term care needs increase. As part of this work, LTQA conducted literature reviews on home- and community-based services (HCBS) in diverse communities with special consideration given to trends in diverse communities' utilization of HCBS, diverse caregivers, and rural communities. This literature review focuses on diverse caregivers.

There are several important cultural elements of caregiving which influence the decision of caregivers to seek help as well as the kind of help they find most useful, with many cultures placing great value in the family caregiver role. Many diverse caregivers do not consider the work they do to be "caregiving," but rather an expected element of family relationships. Studies of caregiver support utilization have found that White caregivers are more likely to utilize formal support than other groups, although many diverse caregivers do have a desire for formal support and have been shown to utilize it more than White caregivers when they have the opportunity to do so. Black caregivers, who typically report a more positive attitude and greater benefits related to caregiving, have also been found to experience greater benefits from the use of respite care. Many of the barriers to formal caregiver support are also the same as those for HCBS in general.

# Methods

The process for this literature review involved a scan of databases for relevant literature related to LTSS and the population groups of interest, as well as the targeted outreach to and investigation of the websites of relevant advocacy groups. Promising programs were identified from existing lists of innovative HCBS programs as well as via general web searches and from the sites of relevant advocacy organizations. The identified relevant literature was then examined in detail in order to identify key findings, which are summarized in this document. A full list of the literature and programs identified can be found in the **Appendix**.



# **Diverse Caregivers**

Meeting the HCBS needs of diverse communities will require understanding and meeting the needs of diverse caregivers as well. Family caregivers are particularly important to diverse communities, who rely on informal care at higher rates than formal care. Among adult aged 70 or older, 44% of Hispanics, 34% of Blacks, and 25% of Whites receive informal caregiving at home (National Hispanic Council on Aging 2017). Caregivers from different communities have unique needs and attitudes towards caregiving, but all face challenges in getting support for themselves and their care recipient.

# **Caregiver Needs and Burden**

### **Level of Care**

Diverse caregivers have unique needs for support. Black caregivers are more likely to provide care for someone who has a chronic physical condition, and more than half of Black and Hispanic caregivers report that they have some or a great deal of difficulty with healthcare tasks such as medication management or wound care and that they have some or a great deal of difficulty with coordinating or arranging for care or other services. More than half of Asian caregivers also report difficulty with healthcare tasks (Diverse Elders Coalition 2021). Among Hispanic caregivers, many embrace the caregiver role and the opportunity to give back to those who sacrificed for them, but are often not aware of sources of guidance, relief, and caregiver support. It has been reported that 45% of Hispanic caregivers experience higher burdens from taking care of an

Among individuals utilizing Older Americans Act (OAA) services, Hispanic and Black caregivers are more likely than White caregivers to care for someone who required assistance with 3 or more Instrumental Activities of Daily Living (IADLs), with that value reaching 99% for Hispanic caregivers, possibly because only those with a higher level of need are seeking support.

older adult or other family member, spending on average 32 hours per week compared to 33% of White caregivers that spend 20 hours per week. 71% of Hispanic caregivers reported that caregiving is taking an emotional toll on them (National Hispanic Council on Aging 2017). Black caregivers are more likely than White caregivers to be providing

greater than 40 hours of care per week (54.3% vs 38.6%) and are more likely to be caring for a person living with dementia (27.1% vs 20.7%) (Fabius et al. 2020).

### **Economic Burden**

One study found that Black caregivers were least likely to report a household annual income above \$20,000, followed by Hispanic caregivers, then White caregivers (Herrera et al. 2013). Average Hispanic caregiver household incomes are well below the national median (\$38,600 vs. \$54,700). Estimates have found that low-income Hispanic family caregivers spend about 44% of their income on caregiving. Hispanic older adults have also been found to be the least prepared segment of the U.S. population for retirement and are unlikely to have retirement savings of any kind. In 2015, 51.5% of Hispanic older adults collected social security benefits. Hispanic and Black older adults are more likely, on a per-capita basis, than White older adults to develop Alzheimer's or other dementias. In a survey of Hispanic caregivers, most caregivers reported that balancing other family and personal responsibilities was among their top three challenges as caregivers. 45% percent also reported communicating with health care providers as a major challenge. Other challenges included finding information and educational resources for caregivers (47%), having enough money to afford caregiving (48%), and understanding government programs such as Medicare, Medicaid, SSI, SNAP, etc. (56%) (National Hispanic Council on Aging 2017). Black caregivers are more likely than White caregivers to provide care to someone who has an income below the federal poverty line (31.7% vs 11.9%) or is eligible for Medicaid (42.2% vs 11.8%). Black caregivers also report worse physical health and greater unmet needs for support compared with White caregivers. Despite these disparities, some analyses of caregivers find that Black caregivers report a more positive appraisal of caregiving than their White counterparts (Fabius et al. 2020).

# Caregiver Role

Several diverse communities report a cultural basis for providing care. In Hispanic families, there is an expectation that younger women will provide care to older adults, whereas in Asian families the oldest son and his wife may be expected to take on the caregiver role (Kally et al. 2014). Both Black and Asian caregivers reported that caring for ill or disabled family members was seen as a responsibility which fulfilled cultural norms, maintained cultural continuity, and strengthened family ties and agreed that

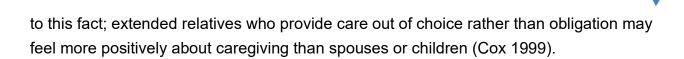
cultural obligation is a reason they provide care. Asian caregivers are more likely to be influenced by expectations related to the concept of filial piety (virtue of respect, care, and obedience towards older family members) (Diverse Elders Coalition 2021).

Familism is a central Hispanic cultural value involving dedication, commitment, and loyalty to the family (Diverse Elders Coalition 2021), and Hispanic cultures often prioritize a respect for the autonomy, dignity, and family role of older adults (National Hispanic Council on Aging 2017). At the same time, 51% of Southeast Asian caregivers and 50.9% of Hispanic caregivers say they are the only person available to provide care (Diverse Elders Coalition 2021).

Black caregivers are more likely to be women, younger, and caring for both children and an older relative at the same time. Black caregivers are also more likely to utilize informal support networks, such as religious organizations, with 91% of Black Americans saying religion is very or somewhat important to them (Diverse Elders Coalition 2021). Black caregivers are more likely involve their church community in the care of older family members (Kally et al. 2014).

Thirty-six percent of Hispanic households provide care to an older adult, compared to 21% of all other households in the United States. Hispanic older adults are also more functionally impaired at younger ages than other older adults, indicating a greater need for home-based care. Mexican American caregivers have also been found to have worse physical health compared with White caregivers (Crist 2009).

Studies were contradictory as to whether Black or White caregivers were more likely to be the child of the care recipient, but consistently found that White caregivers were more likely to be a spouse while Black caregivers were more likely to be an extended relative (Diverse Elders Coalition 2021). Some of the comparatively more positive attitude that Black caregivers have been found to have towards caregiving may be due



In Spanish, there is no exact translation of "caregiver;" the term "cuidador" is sometimes used but does not resonate with many Hispanic people. Caregiving is seen simply as "something that just [needs] to be done - not merely the 'correct' thing to do."

# **Caregiver Support Utilization**

## **Formal and Informal Support**

As with HCBS, there are also parallel patterns among caregivers in the utilization of formal and informal caregiver support. In general, minority caregivers are considered to have larger and stronger informal support networks compared to White caregivers. Caregivers who shared their role with another informal caregiver are much less likely use formal respite services (Chow et al. 2010). Black caregivers are more likely than White caregivers to receive help from other family and friends (82.9% vs 75.5%) (Fabius et al. 2020). A 2010 survey found that Black and White caregivers were less likely than Asian and Hispanic caregivers to receive only informal caregiver support, with Asians being more likely to receive only informal support than Hispanics. White caregivers were most likely to use formal support alone, while Black caregivers were most likely to use both. Within paid supports, Asian American caregivers were the most likely to use inhome respite and financial information supports, while Black caregivers were more likely to use information, education, night respite, and legal information supports, and White caregivers were more likely to attend support groups. White caregivers may seek formal support, such as support groups, more due to comparatively weaker social networks. Although most caregivers used some type of support, whether formal or informal, and there were no differences in the proportions seeking support by race, most caregivers used no more than two types of support, although Black caregivers were somewhat more likely to do so (Chow et al. 2010).



### Respite

Black caregivers have also been shown to utilize respite care more than White caregivers when services are made directly available to them, and they also appear to utilize respite differently. One study found that over the course of a six-month program including Black and White caregivers, Black caregivers were more likely to use respite services and to continue using them for the duration of the program. In addition to typically providing more hours of care per week, Black caregivers also received slightly more informal help than White caregivers prior to the respite program. Interestingly, among respite users, Black caregivers continued to provide the same hours of care themselves and to receive the same hours of help from others, while White caregivers reported a sharp drop in the hours they spent caregiving as well as the informal help they received while they were using the respite services; this indicates that Black caregivers may use respite services to supplement the care they and others are already providing, while White caregivers are more likely to use it as a replacement. During the respite program, White care recipients experienced a decline in ADL function, and both groups of care recipients experienced cognitive decline. The behavioral status of Black care recipients improved, and Black caregivers were found to experience greater gain from respite care than White caregivers (Cox 1999).

# **Other Caregiver Support**

Use of supportive services among all caregivers is low. However, Black caregivers were twice as likely to receive caregiver training and find financial help for the care recipient. Black caregivers also were more likely to report having used any services (not including respite) in the past year and were twice as likely to use two or more services compared with White caregivers. Among those who used services, Black caregivers were more likely to receive assistance from government or community agencies, medical care providers or social workers, religious institutions, and employers. Black caregivers were more likely to report perceived gains and financial strain from caregiving, but less likely to report emotional strain or difficulty participating in their usual activities (Fabius et al. 2020).



# **Older Americans Act Services**

One prominent source of caregiver support is that provided via Title III of the Older Americans Act (OAA). When comparing data from a 2009 survey of OAA participants receiving Title III services with a national representative data sample, Hispanic caregivers were the most likely to access support services from community-based agencies and least likely to use services from Area Agencies on Aging (AAAs), while Black caregivers used services from AAAs the most. White caregivers were the most likely to use support

43% of Hispanic caregivers reported that they received less respite care than they needed, compared to 32% of Black caregivers and 28% of White caregivers.

services paid for by the recipient or family; for Hispanic and Black caregivers, this was the least-used of all options. All races were more likely to utilize support from family and friends than any other source.

# Caregiving for Individuals with Dementia

Caregivers of individuals with dementia often take on a particularly high amount of burden. Black older adults with dementia are more likely than others to age in the community and rely heavily on informal sources of support. Studies specific to the use of respite care have found that Black dementia caregivers report greater need for daytime respite care than White dementia caregivers, potentially because Black caregivers spend more time providing care and are more likely to perform physically demanding tasks like bathing and lifting. However, data from the 2015 National Health and Aging Trends Study and the National Study of Caregiving shows that White dementia caregivers are more likely to use respite services (24.6% vs. 12.8%). Black caregivers may be influenced by anticipation of discrimination in their choice to seek formal support, as well as lack of culturally appropriate services (Parker and Fabius 2020).

Dementia is also stigmatized in some cultures. In Hispanic cultures, the term "dementia" has pejorative connotations, leading to a preference for saying "Alzheimer's disease" instead, which may be more acceptable due to its denotation of a physical rather than mental disease (Oakes et al. 2007). Stigma is also prevalent in Asian cultures and can

potentially contribute to unmet need for support. Chinese American individuals with Alzheimer's have been found to proportionally use fewer Alzheimer's community resources compared to White individuals. Barriers to service use may include stigmas associated with dementia in Chinese culture, lack of knowledge about dementia, and language barriers. Interviewed service professionals have noted that difficulty in communication makes it difficult to understand Chinese American families' situations and what support they want, even when using translators; many also have the perception that families are not interested in formal help and minimize the true extent of their need. At the same time, interviewed Chinese American Alzheimer's caregivers have expressed a desire for more tailored information and services; reluctance to seek

Dementia symptoms among Chinese older adults are often associated with feelings of shame for individuals and their family members, leading many to be discouraged from seeking professional help. Some of this stigma is attributed to the idea of reciprocal relationships between older and younger generations; dementia diminishes the expected role of older adults to share their experience, advice, and wisdom in return for care during old age.

help was tied to limited knowledge of the health care system and previous negative experiences, in addition to stigma. Family caregivers also struggled to find culturally competent services, such as bilingual formal caregivers; Chinese Americans have been found to be three times more likely to use services at Alzheimer's and dementia centers with bilingual staff compared to centers without (Sun et al. 2014).

# **Factors Affecting Access to and Uptake of Caregiver** Services & Resources

Several categories of factors were identified that may influence caregivers' access to and uptake of caregiver services and resources:

- 1. Cultural attitudes towards caregiving,
- 2. Education level,
- 3. Language, and
- 4. Sociopolitical factors.



# **Cultural Attitudes Towards Caregiving**

A study of Korean American older adults and their caregivers found that spousal caregivers were less likely to report unmet need in respite or adult day care than others, such as adult children, which may be due to possible generational differences in perception of care needs. This finding is potentially concerning, as spousal caregivers are likely to be elderly and vulnerable themselves. Female caregivers were also less likely to report unmet need in respite and transportation than males, which may be in part due to differing gendered expectations around caregiving (Casado and Lee 2012).

In general, Black caregivers perceive their situation more favorably than White caregivers, even when they were providing more care with fewer resources. This may be explained by Black caregivers having stronger cultural reasons for providing care than White caregivers, such as religious or spiritual beliefs, as well as familial and generational expectations reading caregiving. This favorable perception may also be influenced by Black caregivers' greater connection to help from family or friends and supportive services (Fabius et al. 2020). Black OAA participants did not benefit from services as much as White participants and were more likely to claim they had no need for HCBS and that their care recipient could continue to live at home if they did not access services (Herrera et al. 2013). Although these positive perceptions are encouraging, they may also come with the risk of underestimating the need of Black caregivers for help; lower reported stress, for example, could lead to Black caregivers not being referred to services at the same rates as White caregivers, even when their level of need is the same (Fabius et al. 2020).

### **Education**

Receiving informal support alone was associated with lower education, while receiving both is associated with care recipients with ADL limitations; caregivers with low levels of strain may be less likely to seek formal support (Chow et al. 2010). A caregiver having a college education and a longer duration of caregiving were also predictive of reported unmet need for adult day care, as higher education has repeatedly been associated with greater awareness of unmet need (Casado and Lee 2012).

OAA services, although reaching the populations most at-risk for institutionalization, were disproportionately reaching the caregivers of minority seniors with above-average levels of education (e.g., 81.2% of Hispanic OAA participants were high school graduates compared to 38.2% of Hispanic older adults nationally). This aligns with previous observations that those with more education likely have more ease in identifying and accessing services. (Herrera et al. 2013).

### Language

As with HCBS, language barriers may make the utilization of formal support more difficult, mainly impacting Hispanic and Asian caregivers; Southeast Asian caregivers are particularly impacted, with as many as 90% of older adults in some communities having limited English proficiency. Hispanic caregivers also often lack access to culturally and linguistically appropriate materials and services, and even providers who speak Spanish may not understand how culture affects care (Diverse Elders Coalition 2021). The success of community-based agencies in reaching Hispanic caregivers may be due to a higher likelihood of providing services in Spanish, addressing cultural health beliefs, and involving community health advisors (Herrera et al. 2013)

## **Sociopolitical Factors**

Many Southeast Asians have also been impacted by the trauma of war and resettlement, low SES, and mass deportations, leading to the potential loss of adult children from the family caregiving structure and distrust of any formal services. All Southeast Asian ethnic groups have poverty rates above the national average, with the Hmong reaching more than twice the national average (27.4% vs. 11.3%). The current political climate has also worsened distrust of institutions and caused greater rates of stress among Hispanic caregivers (Diverse Elders Coalition 2021).

# Strategies to Address Barriers

There are multiple strategies that can be used to support diverse caregivers. Both Black and Hispanic caregivers would benefit from a diverse workforce which understands the community's culture. Black caregivers also need culturally and linguistically competent in-office materials which have a 5th grade reading level or lower and include pictures which include Black older adults and families, as well as the use of traditional methods of contact and outreach are also necessary over more technology-based ones. The inclusion of relevant family members in person-centered care planning as well as expanding the definition of family to accommodate friends, neighbors, and others who

might be in a caregiving role would also help Black caregivers (Diverse Elders Coalition 2021). Faith-based and community efforts are also potential avenues for supporting Black caregivers (Fabius et al. 2020).

Asian and Hispanic caregivers need competent, trained medical interpreters and screening which assesses for difficulty with cultural tasks such as translation, as caregivers who have more difficulty with cultural tasks had poorer health outcomes, higher levels of caregiver strain and depression, had lower ratings of the care they provided their care recipients, and felt less satisfied with the support they received from family and friends. Both groups also have a need for translated in-office materials, culturally competent referrals and resources, in-language caregiver supports groups, and in-language caregiver training (Diverse Elders Coalition 2021). Chinese American Alzheimer's caregivers have expressed a need for appropriate education and community resources for Chinese American families seeking to understand dementia (Sun et al. 2014). Partnerships with community organizations are needed for Hispanic and Southeast Asian caregivers, and disaggregation of data on ethnicity would be particularly helpful for Southeast Asian caregivers while Hispanic caregivers would benefit from programming delivered via community leaders (Diverse Elders Coalition 2021). One study found that 57% of Hispanic caregivers reported a need for assistance with government programs in Spanish and 56% desired trainings on stress management (National Hispanic Council on Aging 2017).

# **Promising Programs**

**Table 1** on pages 14-15 contains a list of promising programs for diverse caregivers which were identified over the course of the literature review (see also "Promising Programs" tab in the **Appendix**). Two of these programs are described in detail in the following table.



# **Savvy Caregiver Program: Caregiver Training**

The Savvy Caregiver Program is an example of a caregiver intervention which has had success in serving diverse caregivers both in its original form as well as in adaptations specifically tailored to particular communities. Savvy Caregiver is a caregiver training program which has the specific aim of reducing stress for caregivers of individuals with Alzheimer's. Elements of the program include building internal caregiver skills, knowledge and self-confidence, engaging the entire family in care, and using community

Key Elements of the Savvy Caregiver Program:

- Understanding the individuals with dementia
- Involving the entire family
- Interactive, culturespecific learning

resources for respite and support. The program is delivered in weekly 2-hour session for six weeks, with materials including a detailed trainer's manual, a caregiver manual, a training videotape, and CD. The original program, when tested on English-speaking Black, Hispanic, and Asian American caregivers, found that caregivers from all three groups demonstrated greater competence, reduced depression, greater tolerance for the memory problems of their care recipients, and better management and improved perception of their situation at six and twelve months after completion of the program. No significant differences were found in the efficacy of the program in helping diverse caregivers compared to White caregivers, although no group experienced an improvement in mastery. (Kally et al. 2014).

Savvy Caregiver has also successfully been adapted into a program specifically targeted at Black dementia caregivers known as "Great Village." The adaptation expanded and strengthened the "Family as a Resource for Caregiving" section of the original program, which discusses how Black caregivers integrate caregiving arrangements and highlights diverse patterns of family structure. Great Village also includes an assessment called "Keeping-It-Real" which includes visualization of the interactions between the caregiver and the institutions which make up their "village." Caregivers receiving Great Village reported reduction in anxiety and depressive symptoms and improvement in mastery, which was not seen when Black caregivers received the standard Savvy Caregiver training (Brewster et al. 2020).

Savvy Caregiver has also been adapted for Spanish-speaking populations in the Cuidando con Respeto program. Before translation, the original caregiver manual was adapted to a sixth-grade reading level, and more colorful, concrete, and pictographic images and graphics were included as well. The adapters followed the advice of focus groups by focusing on strategies for family caregivers rather than individual caregivers and avoiding the use of the term "dementia," in favor of "Alzheimer's disease." The adapters also created a 20-minute telenovela about a family supporting a relative with Alzheimer's, with additional mini-episodes focusing on other elements of the training. These videos were integrated into the slides for the training sessions, which were changed to two three-hour session and included games and other interactive activities. Although comprehensive evaluations of the program's efficacy have not yet been done, participants have had a strong positive response to the program. The vast majority felt more knowledgeable and confident about caregiving, found the novela format useful, agreed they would share the materials with family members. Notably, a majority of participants felt that the information they received about dementia from their health provider was not sufficient, which may be connected to the reported perception that Hispanics with dementia symptoms were less likely to go to the doctor and more likely to attribute the symptoms to "old age" alone (Oakes et al. 2007).



Another intervention which may be of future interest is TCARE (Tailored Caregiver Assessment and Referral System), which was recently evaluated for a potential cultural translation for Korean and Vietnamese caregivers. TCARE is a care management software platform used by care managers to support family caregivers by targeting services to their needs and strengths. In national studies, it

### *Key Elements of TCARE:*

- Language translation
- Culturally-relevant caregiving terminology
- Clarifying the purpose of the assessment

has been shown to reduce caregiver depression and stress and to delay placement in institutions. Researchers from the National Asian Pacific Center on Aging held multiple different focus groups with caregivers and members of the Asian American community in Seattle and found that caregiver and burden concepts do not resonate within Korean and Vietnamese communities, which makes answering some of the TCARE questions difficult. Some of the identity-related questions were considered to be nonsensical or even offensive to caregivers for whom western labels for caregiving "causes shame [and] identity burden." Many considered caregiving to be a standard element of, for example, the duty of a wife to her husband, rather than a separate, additional role only taken on in certain situations. Framing these relationships as one party giving care while the other party receives care was considered offensive due to the implication that the caregiver was looking down on the care recipient. "Caregiver" may also be a term only applied to paid workers. However, although the terminology was different, focus group members did indicate that they struggled with the discrepancy between their caregiver roles and familial roles, supporting the potential usefulness of the TCARE adaptation. Korean and Vietnamese service providers who participated in focus groups often did not understand the purpose and process steps of TCARE, even when they were trained TCARE care managers; one noted that they usually instead engaged in informal conversations with Vietnamese caregivers rather than ask the assessment questions. Researchers proposed detailed five-step plan to pilot and implement the new culturally translated version in Seattle, then statewide (Chun and Jacobs-Vechinski 2018).



**Table 1: Promising Caregiver Programs** 

Program	Description	Link
Asia Pacific Islander Dementia Care Network	The Asian Pacific Islander Dementia Care Network in Los Angeles addresses gaps in the community-based continuum of care for Asians and Pacific Islanders by expanding culturally and linguistically competent services for caregivers and building the capacity of community-based partner agencies in Los Angeles.	<u>Link</u>
BRI Care Consultations	BRI Care Consultation is a care-coaching solution delivered by telephone and email to adults with health conditions and their family or friend caregivers which uses a combination of ongoing assessment, action planning and follow-up. The consultations have been found to result in a decrease in unmet needs, stress and strain, and symptoms of depression for both caregivers and care recipients.	<u>Link</u>
Cuidando con Respeto	Cuidando con Respeto is an adaptation of the Savvy Caregiver Program for Spanish speaking caregivers. The curriculum's family-centered approach incorporates interactive learning activities which allow caregivers to exchange experiences and learn strategies for interacting with family members with Alzheimer's disease.	Link
FAIR (Family Alzheimer's In- Home Respite Program)	FAIR provides caregivers of individuals with Alzheimer's disease or a related dementia in West Virginia with respite care. Family caregivers can receive up to sixteen hours of respite per week, with the fee depending on the income of the care recipient.	<u>Link</u>
Great Village	Great Village is an adaptation of the Savvy Caregiver program aimed at Black caregivers. The adaptation makes various changes to program content to be more engaging for Black caregivers and expands the segment of the program focused on family caregiving.	<u>Link</u>
Resources for Enhancing Alzheimer's Caregivers Health (REACH)	REACH II is a structured multi-component caregiver intervention based on an individualized assessment of caregiver needs. Interventions are tailored to individualized risk profiles based on depression, burden, self-care and healthy behaviors, social support, and problem behaviors. Caregiver	<u>Link</u>

	interventions include strategies selected to address clients' individualized needs.	
Savvy Caregiver	Savvy Caregiver is a psycho-educational training program intended to train families and others about the unfamiliar role they face as caregivers of a relative or friend with Alzheimer's disease or dementia.	<u>Link</u>
Take Time Texas	The initiative is called Take Time Texas offers short-term respite care services to family members who care for a person of any age with any chronic health condition or disability. Both in-home and out-of-home respite care are available according to the needs of the caregiver.	<u>Link</u>
TCARE (Tailored Caregiver Assessment and Referral System)	TCARE is a care management protocol designed to aid care managers in supporting family caregivers of adults of any age with chronic or acute health conditions.	Link
Tele-Savvy	Tele-Savvy is an online version of the Savvy Caregiver program. Results indicate that it can achieve similar levels of success to the in-person program.	<u>Link</u>





### **Long-Term Quality Alliance**

Long-Term Quality Alliance (LTQA) is a 501(c)3 membership organization aimed at improving outcomes and quality of life for people who need long-term services and supports (LTSS), and

their families. LTQA advances person- and family-centered, integrated LTSS through research, education, and advocacy. For more information, visit Itqa.org.

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### **Bibliography**

Brewster GS, Epps F, Dye CE, Hepburn K, Higgins MK, Parker ML. The Effect of the "Great Village" on Psychological Outcomes, Burden, and Mastery in African American Caregivers of Persons Living With Dementia. J Appl Gerontol. 2020 Oct;39(10):1059-1068. doi: 10.1177/0733464819874574. Epub 2019 Sep 19. PMID: 31535922; PMCID: PMC7080571.

Casado BL, Lee SE. Access barriers to and unmet needs for home- and community-based services among older Korean Americans. Home Health Care Serv Q. 2012;31(3):219-42. doi: 10.1080/01621424.2012.703540. PMID: 22974082.

Chow JCC, Auh EY, Scharlach AE, Lehning AJ, & Goldstein C. Types and sources of support received by family caregivers of older adults from diverse racial and ethnic groups. Journal of Ethnic & Cultural Diversity in Social Work. 2010;19(3): 175-194. doi: 10.1080/15313204.2010.499318

Chun H, Jacobs-Vechinski J. Cultural Translation of TCARE for Korean and Vietnamese Caregivers. https://napca.org/wp-content/uploads/2018/06/Cultural-Translation-of-TCARE-for-Korean-and-Vietnamese-Caregivers Final-Report.pdf. Published March 2018. Accessed July 31, 2021.

Crist JD, McEwen MM, Herrera AP, Kim SS, Pasvogel A, Hepworth JT. Caregiving burden, acculturation, familism, and Mexican American elders' use of home care services. Res Theory Nurs Pract. 2009;23(3):165-180. doi:10.1891/1541-6577.23.3.165

Cox C. The experience of respite: Meeting the needs of African American and White caregivers in a statewide program. Journal of Gerontological Social Work. 1999 Feb;30(3-4):59-72. doi: 10.1300/J083v30n03 06

Diverse Elders Coalition. Caring for Those Who Care: Resources for Providers: Meeting the Needs of Diverse Family Caregivers. https://www.diverseelders.org/wp-content/uploads/2021/03/DEC-Toolkit-Final-R2.pdf. Published March 2021. Accessed July 31, 2021.

Fabius CD, Wolff JL, Kasper JD. Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans. Gerontologist. 2020;60(7):1244-1253. doi:10.1093/geront/gnaa042

Herrera AP, George R, Angel JL, Markides K, Torres-Gil F. Variation in Older Americans Act caregiver service use, unmet hours of care, and independence among Hispanics, African Americans, and Whites. Home Health Care Serv Q. 2013;32(1):35-56. doi:10.1080/01621424.2012.755143

Kally Z, Cote SD, Gonzalez J, Villarruel M, Cherry DL, Howland S, Higgins M, Connolly L, Hepburn K. The Savvy Caregiver Program: impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. J Gerontol Soc Work. 2014;57(6-7):681-93. doi: 10.1080/01634372.2013.850584. Epub 2014 May 12. PMID: 24820315.

National Hispanic Council on Aging. 2017 Status of Hispanic Older Adults: Insights from the Field -Caregivers Edition. https://www.diverseelders.org/resource/2017-status-of-hispanic-older-adultsinsights-from-the-field-caregivers-edition/. Published September 2017. Accessed July 31, 2021.

Oakes SL, Hepburn K, Ross JS, Talamantes MA, Espino DV. Reaching the heart of the caregiver. Clinical gerontologist. 2007 Jan;30(2):37-49. doi: 10.1300/J018v30n02 04

Parker LJ, Fabius CD. Racial Differences in Respite Use among Black and White Caregivers for People Living with Dementia. J Aging Health. 2020 Dec;32(10):1667-1675. doi: 10.1177/0898264320951379. Epub 2020 Aug 21. PMID: 32819177.

Sun F, Mutlu A, Coon D. Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. Clinical gerontologist. 2014 Mar;37(2):120-38. doi: 10.1080/07317115.2013.