



# Caring for Those Who Care

**Resources for Providers:  
Meeting the Needs of Diverse Family Caregivers**





# DIVERSE ELDERS COALITION



- **National Asian Pacific Center on Aging (NAPCA)**  
[www.napca.org](http://www.napca.org)
- **National Caucus and Center on Black Aging (NCBA)**  
[www.ncba-aging.org](http://www.ncba-aging.org)
- **National Hispanic Council on Aging (NHCOA)**  
[www.nhcoa.org](http://www.nhcoa.org)
- **National Indian Council on Aging (NICOA)**  
[www.nicoa.org](http://www.nicoa.org)
- **SAGE: Advocacy & Services for LGBTQ+ Elders**  
[www.sageusa.org](http://www.sageusa.org)
- **Southeast Asia Resource Action Center (SEARAC)**  
[www.searac.org](http://www.searac.org)



**LAUREN PONGAN**  
National Director  
Diverse Elders Coalition

**DEAR READER,**

Since its founding more than 10 years ago, the Diverse Elders Coalition (DEC) has advocated for policies and programs that improve aging in our communities as racially and ethnically diverse people; American Indians and Alaska Natives; and and lesbian, gay, bisexual, queer, questioning, and/or transgender people. Family caregiving, a field that is receiving increased attention nationally, is no exception. Ultimately, the health and well-being of diverse older adults depends on the health of the people providing their care.

As a coalition, we're working to make sure that the needs of diverse elders and their caregivers are studied, considered, and addressed. By 2030, 72.8 million people—more than one in five people in the United States—will be age 65 or older. The number of older Americans will not only double from 2010 to 2050, but the older population will also be more diverse. By 2030, nearly 3 in 10 older Americans will identify as a member of a diverse or underrepresented group. At the same time, the lesbian, gay, bisexual, queer, questioning and transgender (LGBTQ+) older population will more than double its current population of three million people.<sup>1</sup>

That brings us to you—healthcare and social services providers who are ready to learn how to support diverse family caregivers. This toolkit offers topline information on what providers need to know, and key pieces from our comprehensive cultural competency training curriculum, **Caring for Those Who Care: Meeting the Needs of Diverse Family Caregivers**. Whether you've already attended one or more of our trainings, or this is your first time looking into what's available to help you support diverse family caregivers, we think you'll find these resources to be invaluable in building a more welcoming, supportive practice.

Thank you,

A handwritten signature in black ink, appearing to read 'Lauren Pongan'.

<sup>1</sup>[www.lgbtagingcenter.org/resources/pdfs/SAGE%20Caregiver%20Guide%20Final%20Interactive.pdf](http://www.lgbtagingcenter.org/resources/pdfs/SAGE%20Caregiver%20Guide%20Final%20Interactive.pdf)

## About this Toolkit

**The Caring for Those Who Care: Meeting the Needs of Diverse Family Caregivers Curriculum**, as well as this toolkit, were created by the six members of the Diverse Elders Coalition, with generous funding from The John A. Hartford Foundation.

Based in New York City, The John A. Hartford Foundation is a private, nonpartisan philanthropy dedicated to improving the care of older adults. Established in 1929, the Foundation has three priority areas: creating age-friendly health systems, supporting family caregiving, and improving serious illness and end-of-life care.

For more information, visit [www.johnahartford.org](http://www.johnahartford.org) and follow @johnahartford.



The  
**John A. Hartford**  
Foundation



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# **What Providers Should Know Factsheets**

# What Providers Should Know About African American and Black Family Caregivers



## There is no uniform ethnicity, culture, language, and/or experience among those who identify as African American/Black.

(Kusow, 2014)

### ● There are distinctions within “African American” and between “African American” and “Black” that have cultural and linguistic significance.

- A US-born person with African descent is considered African American
- A majority of African immigrants identify with their respective ethnicities of origin
- Afro-Cubans, Afro-Caribbeans, Afro-Brazilians, Afro-Haitians, and Afro-Latino people may or may not identify with the term “African American”

## HEALTH DISPARITIES

- African American and Black people have a greater risk for heart disease, stroke, high blood pressure, Alzheimer’s/dementia, and diabetes.
- African American and Black caregivers are more likely to provide care for someone who has a long-term/chronic physical condition (NAC, AARP, 2015).
- Amidst health and socioeconomic disparities, African American/Black families remain resilient.
  - Higher rates of grandparent caregivers (Tang et al., 2015)
  - Complex family structures
  - Multiple caregivers
  - **Familism:** defined as a social structure where the needs of the family are more important and take precedence over the needs of any family members

## CULTURAL COMMITMENT TO CARE

- African American/Black caregivers reported that “caring for ill or disabled family members was seen as a responsibility (Scharlach et al., 2006).
  - Fulfilled cultural norms
  - Maintained cultural continuity
  - Strengthened family ties
- On average, African American/Black caregivers agree that cultural obligation is a reason they provide care. However, this can lead to challenges.
  - African American/Black caregivers were more likely to be women, younger, and “sandwiched” between caring for more than one person (NAC, AARP, 2015)
  - Grandparent caregivers are disproportionately women, younger, less educated, and living in poverty, representing a highly vulnerable population (Minkler et al., 2005)
  - More likely to utilize informal support networks, such as religious organizations



## IN OUR SURVEY OF AFRICAN AMERICAN AND BLACK FAMILY CAREGIVERS:


**54%** report some or great deal of difficulty with healthcare tasks such as medicating management or caring for wounds


**56%** report some or great deal of difficulty with coordinating or arranging for care or services from doctors, nurses, social workers, etc.

**34%** agree that they are the only person available to provide care for a recipient

**31%** agree that caregiving had negative effects on their physical/emotional health

**31%** agree to feeling isolated due to caregiving

 A need for culturally competent formal support services

 Less personal time, limited engagement in other activities, more stress and pressure

## HOW CAN PROVIDERS BETTER SUPPORT AFRICAN AMERICAN AND BLACK FAMILY CAREGIVERS?

- ◆ **Recruit, promote, and support a diverse interdisciplinary workforce that understands/represents the culture of the community**

  - Allows for easier communication between hospital case managers and home liaisons
  - More opportunities to identify caregivers and to deliver effective caregiving training
- ◆ **Development of culturally and linguistically competent in-office materials to deliver information such as medication management and caregiving training**

  - Ensure that materials are written at a 5th grade reading level or lower
  - Include pictures that reflect African American older adults and families
- ◆ **Identify and include relevant family members in person-centered care planning**

  - Revise Patient Demographic Forms and/or Adult History forms to identify whether a patient is providing care for a friend or family member
  - Expand your organization's definition of "family" to include friends, neighbors, and others outside of the traditional family structure
- ◆ **Utilize traditional modes of contact/outreach in identification and promoting supportive services, education, and training (AARP, 2018; Navaie, 2011)**

  - In-person meetings
  - Telephone
  - Print material (delivered by mail)
  - Newsletter



# What Providers Should Know About American Indian and Alaska Native Family Caregivers



**There are 574 federally recognized American Indian/Alaska Native tribes. Each tribe has their own nation within a larger nation, regardless of national and state borders.**

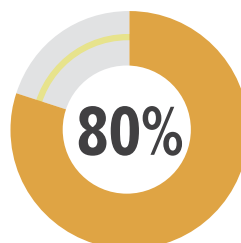
- **Tribal/Self Governance is essential to American Indian/Alaska Native culture. Tribal governments are responsible for a broad array of services, including:**
  - Education
  - Law Enforcement
  - Judicial Systems
  - Healthcare
- **Family is the center unit of American Indian/Alaska Native culture. Taking care of the family is part of traditional values, and Elders are highly regarded among family structures and in society (Scharlach et al., 2006; p. 139-140).**

## HEALTH DISPARITIES

- **Diseases of the heart, cancer, and diabetes are leading causes of death for American Indian/Alaska Natives.**
  - AI/AN are 2x as likely than whites to have diabetes (CDC, 2017)
  - Diabetes is a strong risk factor for heart disease—the leading cause of death
  - Common types of cancer include prostate, breast, lung, colon, and kidney
- **Rural tribal communities are geographically isolated from care services and resources.**
  - Exacerbates health disparities
  - Lack of caregiver training

## CULTURAL COMMITMENT TO CARE

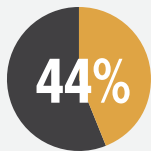
- **Many American Indians and Alaska Natives express a distrust of the majority culture and government due to a history of poverty, displacement, and discrimination. As a result, caregivers are more reluctant to use formal supportive services (Scharlach et al., 2006).**
- **American Indians and Alaska Natives often feel a strong cultural commitment to caring and a reliance on family and tribe for support.**
  - Healthcare services provided by tribal health providers
  - Community Health Representatives through Indian Health Services
  - Local tribal community-based organizations
- **On average, AI/AN caregivers agree that cultural obligation is a reason they provide care.**



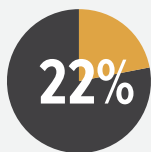
**80% OF AMERICAN INDIAN/ALASKA NATIVE CAREGIVERS AGREED OR STRONGLY AGREED THAT CULTURAL COMMITMENT TO CAREGIVING WAS A REASON THAT THEY PROVIDED CARE TO A LOVED ONE.**



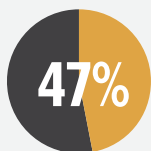
## IN OUR SURVEY OF AMERICAN INDIAN AND ALASKA NATIVE FAMILY CAREGIVERS:



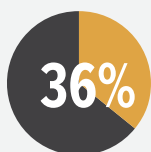
agree that they are the only person to help their care recipients



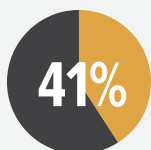
report 0 family, friends, neighbors who assisted, helped, or supported them



indicate paying expenses related to relatives or friend's health condition or disabilities



report some or great deal of difficulty with healthcare tasks such as medication management or wound care



report some or great deal of difficulty with coordinating or arranging for care services from doctors, nurses, and social workers



One in five respondents state that their doctors or other healthcare providers did not know about the care they provided to others



More likely to pay for caregiving expenses than African American and Black, Asian, Southeast Asian, or Hispanic/Latino caregivers

## HOW CAN PROVIDERS BETTER SUPPORT AMERICAN INDIAN AND ALASKA NATIVE FAMILY CAREGIVERS?

- **To provide for American Indian/Alaska Native caregivers it is necessary to be aware of their roots in social, historical, cultural, economic, and environmental issues**

  - Strengthen tribal and community-based organizations to increase capacity of programming
  - “Shared” dedication rather than reinvent the wheel
- **Build relationships with tribal communities in your region. This can include developing 1:1 relationships with tribal leaders, elders, Community Health Representative, and tribal members.**
- **Develop culturally and linguistically competent in-office material for training, information on caregiving, disease information, and intervention outreach**

  - Avoid words such as “caregiver burden”
  - 6th grade reading level or lower
  - Use images with representation of American Indians/Alaska Natives
- **Consult with local tribal leaders, elders, local institutions in local tribal communities in disseminating print material and to develop or increase capacity programming**

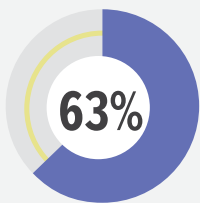
  - Increased visibility of print material to reduce stigma, provide disease information, and caregiver training/information
  - Tribal leaders, elders are the centerpoint of tribal communities

# What Providers Should Know About Chinese American & Korean American Family Caregivers

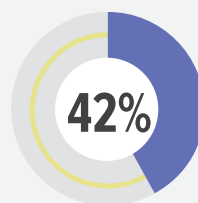


The umbrella group “Asian American and Pacific Islander” or AAPI consists of more than 50 different ethnicities with over 100 languages spoken.

- Chinese are the largest Asian American ethnic group aged 55 and older (NAPCA, 2013).



OF THE CHINESE POPULATION ARE FOREIGN BORN (PEW, 2015)



OF THE FOREIGN-BORN POPULATION IS AGED 50 AND OLDER

## HEALTH DISPARITIES

- Historically, AAPI communities have faced significant barriers to accessing affordable health insurance and quality health services, and these barriers have contributed to health disparities.
  - Asian American, Native Hawaiian, and other Pacific Islander communities are likely to lack health insurance coverage
  - Health conditions that are common in the AAPI community—like diabetes, obesity, cancer, HIV/AIDS and mental illness—often go undiagnosed and untreated. (WHIAAPI)

## CULTURAL COMMITMENT TO CARE

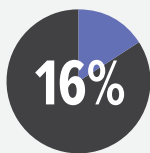
- On average, Chinese American caregivers agree that cultural obligation is a reason they provide care for their relative or friend.
- AAPI caregivers are more likely to adopt or be influenced by expectations related to the concept of filial piety (virtue of respect, care, obedience).
- Chinese and Korean family caregivers reported that caring for ill or disabled family members (Scharlach et al., 2006):
  - Fulfilled cultural norms
  - Maintained cultural continuity
  - Strengthened family ties

## HOW CAN PROVIDERS BETTER SUPPORT CHINESE AMERICAN AND KOREAN AMERICAN FAMILY CAREGIVERS?

- Utilize culturally competent, trained Medical Interpreters when speaking to AAPI family caregivers
  - Limited English proficient patients were 27% more likely to be readmitted (Diamond et al., 2017)
- Assess for difficulty with cultural tasks in caregiver & patient screening
  - Caregivers who reported high difficulty with cultural tasks had poorer health outcomes
  - Edit caregiver burden screening tools to collect information about caregiving responsibilities

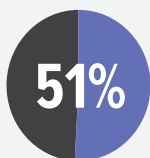


## IN OUR SURVEY OF CHINESE AMERICAN AND KOREAN AMERICAN FAMILY CAREGIVERS:

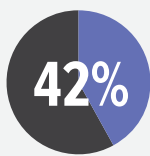


report some or a great deal of difficulty assisting with cultural tasks, such as:

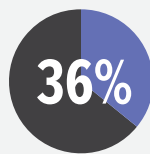
- Overcoming language barriers when talking with healthcare or service providers
- Translating health-related information into main language
- Legal issues related to immigration or naturalization procedures



report some or a great deal of difficulty with healthcare tasks such as medication management and caring for wounds



report some or great deal of difficulty with coordinating or arranging for care or services from doctors, nurses, social workers, etc.



of Korean American caregivers agreed or strongly agreed that caregiving had negative effects on their emotional health



**Caregivers who report more difficulties performing cultural tasks:**

- Have higher levels of four types of caregiver strain and depression
- Provided lower ratings of the quality of healthcare provided to their care recipients
- Report feeling less satisfied with support from family members or friends

## HOW CAN PROVIDERS BETTER SUPPORT CHINESE AMERICAN AND KOREAN AMERICAN FAMILY CAREGIVERS?

*continued*

### • Develop translated in-office materials for disease knowledge, treatments, and training

- In-language materials help mitigate the limited opportunities to speak to providers due to time constraints
- In-office materials are seen by AAPI older adults as the most impactful in providing health-related information (AARP, 2018)

### • Provide culturally competent referrals and resources

- Dissemination of culturally competent in-office material for training and information
- Affordable and in-language referrals

### • Develop in-language caregiver support groups

- Resolve social and linguistic isolation
- Provide support network for older adult LEP caregivers

### • Develop in-language caregiver education/training workshops

- Advertisements and materials that reflect AAPI older adults and caregivers
- Ensure that materials are translated both linguistically and culturally

**FOREIGN-BORN CAREGIVERS IN THE US ARE OLDER, HAVE LOWER EDUCATIONAL DEGREES, LOWER INCOME, AND ASSIST MORE WITH CULTURE-RELATED TASKS, LIKE TRANSLATING HEALTHCARE INFORMATION FROM ENGLISH.**



# What Providers Should Know About Southeast Asian American Family Caregivers



Southeast Asian American (SEAA) is a political and racial identity for a subgroup of Asian Americans who were primarily resettled in the United States as refugees in the 1970s. The label includes:

## Cham

A MUSLIM MINORITY GROUP

## Khmer

## Khmer Loeu

OR HIGHLAND KHMER

## Hmong

## Iu Mien

OR MIEN

## Khmu

## Lao

OR LAO LOUM/LOWLAND LAO

## Taidam

## Khmer Kampuchea Krom

OR ETHNIC KHMER

## Montagnards

OR HIGHLANDERS OF SEVERAL DIFFERENT ETHNIC GROUPS

## Vietnamese

\*CERTAIN ETHNIC CHINESE ALSO HAVE HERITAGE IN CAMBODIA, LAOS, AND VIETNAM.

## HEALTH DISPARITIES

- **Limited English proficiency rates for Southeast Asian American communities are between 40-50%. For elders, those numbers can jump as high as 90%.**
- **SEAs are affected by the traumas of war and resettlement, low socioeconomic status, and recent mass deportations.**
  - Inadequate access to mental health services
  - Adult children removed from family caregiving structure
  - Promotes distrust of any formal services
- **Poverty rates in all SEAA ethnic groups are above the national average (11.3%).**
  - Hmong 27.4%
  - Cambodian 18.2%
  - Vietnamese 13%
  - Laotian 12.2%

## CULTURAL COMMITMENT TO CARE

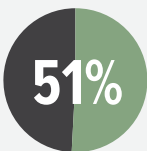
- **Family and Respect are two pillars of the Vietnamese traditional values.**
- **Vietnamese caregivers reported that caring for ill or disabled family members (Scharlach et al., 2006):**
  - Fulfilled cultural norms
  - Maintained cultural continuity
  - Strengthened family ties
- **On average, SEAA caregivers agree that cultural obligation is a reason they provide care for their relative or friend.**

ABOUT 1.1 MILLION SOUTHEAST ASIANS WERE RESETTLED DURING THE VIETNAM WAR AND CAMBODIAN GENOCIDE. INADEQUATE RESETTLEMENT SUPPORT UPON ARRIVAL LED TO MANY BARRIERS FOR SEAS, AMONG THEM HIGH RATES OF LIMITED ENGLISH PROFICIENCY.





## IN OUR SURVEY OF SOUTHEAST ASIAN AMERICAN FAMILY CAREGIVERS:



agree that they are the only person available to provide care to their care recipients



report some or a great deal of difficulty assisting with cultural tasks, such as translating health information into their native language



report that their healthcare providers did not know about the care they provided to their loved one(s)



One quarter of those surveyed agree that caregiving had negative effects on their physical/emotional health

- Less personal time, limited engagement in other activities, more stress and pressure
- **22.7%** agreed to feeling isolated due to caregiving
- **14.3%** reported feeling more symptoms of depression sometimes or often

## HOW CAN PROVIDERS BETTER SUPPORT SOUTHEAST ASIAN AMERICAN FAMILY CAREGIVERS?

- **Utilize culturally competent, trained Medical Interpreters when speaking to Southeast Asian American family caregivers**
- **Assess for difficulty with cultural tasks in caregiver & patient screening**
  - Caregivers who reported high difficulty with cultural tasks had more poor health outcomes than patients who reported low difficulty
- **Develop translated culturally competent in-office materials for disease knowledge, treatments, outreach and training**
  - Reduction of stigma surrounding diseases
  - Lower readmission rates
  - Higher caregiver satisfaction
- **Create partnerships and provide funding/support to community-based organizations that provide services to SEAA communities**
- **Disaggregate data that is collected on intake forms and in healthcare settings**
  - Better understanding of challenges and resiliencies unique to SEAA communities
- **Provide culturally competent referrals and resources to resolve high difficulty with cultural tasks**
- **Development of in-language caregiver support groups**
  - Nearly half of SEAA caregivers indicate being the only person available to provide care
  - Improve mental health and reduce isolation
  - Creation of safe place to share concerns and learn from others
  - Better caregiver outcomes

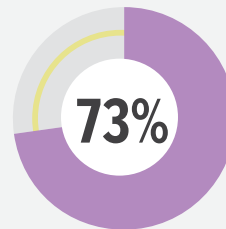
# What Providers Should Know About Hispanic and Latino Family Caregivers



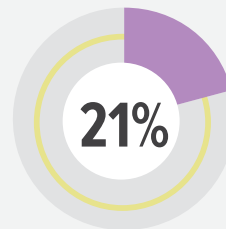
The Hispanic/Latino community is the largest ethnic minority group in the US, comprising 18.1% of the total US population.

(Census, 2018)

- **Culture and language have a big impact on access to care and supports.**
  - More likely to rely on family and less likely to seek outside sources (Flores et al, 2009)
  - Spanish-speaking Hispanic/Latino family caregivers report feeling unprepared resulting in isolation and separation from social life (AARP)
- **There is really no good word for “caregiver” in Spanish. The word “cuidador” is sometimes used, but it does not resonate with many Hispanic and Latino people (NHCOA).**



73% OF US HISPANIC/LATINO HOUSEHOLDS SPEAK SPANISH AT HOME (PEW, 2017)



21% 1 IN 5 OLDER AMERICANS WILL BE HISPANIC/LATINO BY 2060 (ACL, 2017)

## CULTURAL COMMITMENT TO CARE

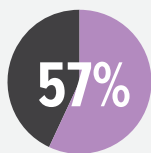
- **Familism: a central Latino cultural value. It involves dedication, commitment, and loyalty to family. Regularly spending time with one’s immediate and extended family is part of familism. It also involves seeking the family’s advice for important decisions.**
- **Hispanic/Latino families tend to adopt or be impacted by the value of familism (McClearly et al, 2013).**
  - 27% of Hispanics/Latinos living in the US live in multigenerational family households
  - Caregiving is described as “something that just needed to be done—not merely the ‘correct’ thing to do”

## HEALTH DISPARITIES

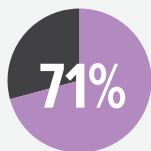
- **Barriers to service utilization**
  - Lack of culturally and linguistically appropriate materials and services
  - Even when providers speak Spanish, they don’t understand how culture affects care
- **Disproportionately affected by Alzheimer’s and related dementias, diabetes, and poor mental health**
  - Hispanic/Latino caregivers are more likely to be affected by caregiver strain and depression
  - Recent political climate has promoted fear among the Hispanic/Latino population
    - Exacerbates distrust in institutional entities
    - Promotes stress and worsens health outcomes



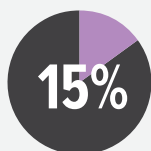
## IN OUR SURVEY OF HISPANIC/LATINO FAMILY CAREGIVERS:



report some or great deal of difficulty with personal care tasks and healthcare tasks such as medication management, wound care



report some or great deal of difficulty with arranging for care or services from doctors, nurses, social workers, or other professionals



report some or great deal of difficulty with cultural tasks, such as:

- Overcoming language barriers when talking with healthcare or service providers
- Translating health-related information into main language
- Legal issues related to immigration or naturalization procedures



The lack of informal and formal support increases strain for caregivers

- **50.9%** agree that they are the only person to help care recipients
- **30.3%** report agreed to feeling more isolated due to caregiving
- **31.3%** agreed that caregiving had negative effects on their physical/emotional health
- **16.3%** reported feeling more symptoms of depression sometimes or often

## HOW CAN PROVIDERS BETTER SUPPORT HISPANIC AND LATINO FAMILY CAREGIVERS?

- **Recruit, promote, and support a diverse workforce that understands/represents the culture of the community**
  - Cultural representation among providers is important for Hispanic/Latino caregivers and older adults (Terlizzi et al., 2019)
  - Easier communication, improved patient and caregiver outcomes
- **Utilize culturally competent, trained Medical Interpreters when speaking to Hispanic/Latino family caregivers and older adults**
- **Assess for difficulty with cultural tasks in caregiver & patient screening**
  - Caregivers who reported high difficulty with cultural tasks had more poor health outcomes than patients who reported low difficulty
- **Partner with community-based organizations to provide culturally competent referrals and resources**
- **Develop translated culturally competent in-office material to provide information and training**
- **Utilize community leaders to recruit and deliver comprehensive, innovative programming amongst Hispanic/Latino older adults and caregivers**
  - Opportunity to provide information around different disease stigma
- **Development of in-language caregiver support groups**
  - May lead to improved caregiver outcomes
  - Opportunity to provide caregiver training workshops

# What Providers Should Know About Lesbian, Gay, Bisexual, Queer, Questioning and Transgender (LGBTQ+) Family Caregivers



**Lesbian, gay, bisexual, queer, questioning and transgender (LGBTQ+) family caregivers have challenges and resiliencies unique to their identities.**

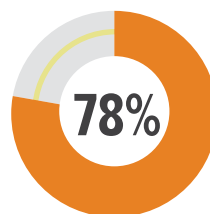
- **Being gay was a mental illness until the 1980s. Marriage equality just happened in 2015. Older adults have had not an experience of tolerance—theirs has been an experience of survival.**
- **Family of Choice:** many LGBTQ+ people become estranged from their biological families because of their LGBTQ+ identities, and instead create “families of choice” from friends, peers, and neighbors. In many cases, these are the people providing care for LGBTQ+ community members, who are less likely to be married, less likely to have children, and more likely to live alone.

## CULTURAL COMMITMENT TO CARE

- **Many people who identify as LGBTQ+ rely on families of choice to provide care.**
  - Four times less likely to have children and twice as likely to be single
  - Family of choice not frequently recognized by formal services
- **LGBTQ+ adults become caregivers at a much higher rate than general caregiving population (AARP & National Alliance for Caregiving, 2015).**
  - LGBTQ+ caregivers make up around 9% of the caregiving population
  - This number could be higher, as some people may be afraid to come out due to discrimination

## HEALTH DISPARITIES

- **Caregivers who identify as a gender and/or sexual minority report being discriminated by healthcare providers and bureaucratic health systems (Fredriksen-Golden, Jen, Bryan, & Goldsen, 2016).**
  - Hesitance about reaching out to services and seeking guidance with care
  - Rely more heavily on support from family, friends, and neighbors
- **Transgender people experience widespread discrimination in health care, employment, and housing (Bradford et al., 2013).**
- **Because of a history of discrimination and barriers in health care as mentioned (family of choice), LGBTQ+ caregivers and recipients may not get the information, education, training, and other resources necessary to provide high quality and sustainable care.**

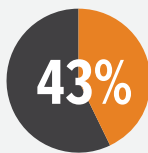


**78% OF LGBTQ+ OLDER ADULTS GO BACK IN THE CLOSET UPON ENTERING A NURSING HOME OR ASSISTED LIVING FACILITY.**

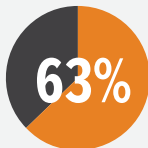




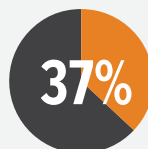
## IN OUR SURVEY OF LGBTQ+ FAMILY CAREGIVERS:



report some or great deal of difficulty with healthcare tasks such as medication management or caring for wounds



report some or great deal of difficulty coordinating or arranging for care services from doctors, nurses, social workers, etc.



More than a quarter agree to feeling isolated due to caregiving

- Less personal time, limited engagement in other activities, more stress and pressure
- Higher incidence of isolation than other groups



LGBTQ+ caregivers are more likely to report feeling they are the only person available to provide care than other diverse groups

- 45% agree that they are the only person available to provide care
- Other family members may make unfair assumptions that the LGBTQ+ person “has no partner or kids” and thus has the time to care for an older adult



LGBTQ+ caregivers are less likely to seek help because they are afraid of discrimination

## HOW CAN PROVIDERS BETTER SUPPORT LGBTQ+ FAMILY CAREGIVERS?

- **Collect information on gender identity and sexual orientation to better understand the needs your patients and caregivers**
  - Edit demographic intake tools to collect information about sexual orientation and gender identity
  - Reflect the words people use to describe their identities and relationships
- **Provide culturally competent referrals and resources**
- **Develop and leverage partnerships with CBOs to refer caregivers to LGBTQ+-friendly training and support groups**
- **Create welcoming, supportive, and safe environments for LGBTQ+ caregivers and older adults**
  - Utilization of posters, signs, rainbow flag on front door to welcome LGBTQ+ adults, but only after a training and policy audit to ensure that services are welcoming
  - Eliminate fear of judgment, discrimination, and rejection
  - Provide ongoing LGBTQ+ competency training to staff
  - Develop culturally competent advertisements, brochures, pamphlets that reflect LGBTQ+ constituents
- **Develop programs to engage LGBTQ+ older adults and/or caregivers**
- **Ensure that your organization’s nondiscrimination policy includes sexual orientation and gender identity, and any use of the word of “family” makes it clear that chosen families also count**





# **Diverse Family Caregiving Resources**

# Are Diverse Family Caregivers Getting the Help They Need?



Findings from the Diverse Elders Coalition’s caregiving community survey indicates that many caregivers in communities of color, LGBTQ+ communities, and American Indian and Alaska Native communities are having difficulty with healthcare, financial, and legal tasks for their care recipients. However, professional supportive services in these areas are underutilized.

Percentage of caregivers who:

TASK	help with this task	report difficulty with this task	get professional help for this task
Personal care tasks such as bathing and dressing.....	<b>47.1%</b>	<b>68.8%</b>	<b>39.6%</b>
Daily household chores or errands such as housework, laundry or shopping .....	<b>83%</b>	<b>51.4%</b>	<b>37.1%</b>
Healthcare tasks at home such as taking medications and caring for wounds.....	<b>61.7%</b>	<b>51.8%</b>	<b>36.6%</b>
Coordinating or arranging for care or services from doctors, etc. ....	<b>72.8%</b>	<b>58.3%</b>	<b>35.2%</b>
Emotionally dealing with their health problems or disabilities.....	<b>74.7%</b>	<b>72.2%</b>	<b>36.3%</b>
Getting information about their health problems or disabilities.....	<b>73.9%</b>	<b>56.1%</b>	<b>44.3%</b>
Finding a place where they could live to get need care or services.....	<b>37.6%</b>	<b>63.8%</b>	<b>35.6%</b>
Getting enrolled in Medicare, Medicaid, other insurance.....	<b>48%</b>	<b>54.2%</b>	<b>47.4%</b>
Getting services paid for by Medicare, Medicaid, etc. ....	<b>52.7%</b>	<b>50.1%</b>	<b>50.1%</b>
Legal issues such as making a will, power of attorney or guardianship, completing advance directives.....	<b>40.9%</b>	<b>58.1%</b>	<b>34.2%</b>
Financial issues related to health such as estate planning, managing assets, property or bank accounts .....	<b>43.1%</b>	<b>54.4%</b>	<b>28.7%</b>
Legal issues related to immigration or naturalization procedures .....	<b>21.4%</b>	<b>60.7%</b>	<b>37.8%</b>
Translating health-related information into their primary language.....	<b>44.6%</b>	<b>50.3%</b>	<b>38.5%</b>

# National Caregiving Resources



DIVERSE  
ELDERS  
COALITION

## DIVERSE ELDERS COALITION

[www.diverseelders.org](http://www.diverseelders.org)

Founded in 2010, the Diverse Elders Coalition (DEC) advocates for policies and programs that improve aging in our communities as racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual and/or transgender (LGBTQ+) people.



## NATIONAL ASIAN PACIFIC CENTER ON AGING (NAPCA)

[www.napca.org](http://www.napca.org)

Founded in 1979, NAPCA is the nation's leading advocacy and service organization committed to the dignity, well-being, and quality of life of Asian Americans and Pacific Islanders (AAPIs) as they age.

## NATIONAL CAUCUS AND CENTER ON BLACK AGING (NCBA)

[www.ncba-aging.org](http://www.ncba-aging.org)

The National Caucus & Center on Black Aging, Inc. was founded in 1970 to ensure the social and economic concerns of African American older adults were included on the 1971 White House Conference on Aging agenda.

## NATIONAL HISPANIC COUNCIL ON AGING (NHCOA)

[www.nhcoa.org](http://www.nhcoa.org)

The National Hispanic Council on Aging (NHCOA) is the leading national organization working to improve the lives of Hispanic/Latino older adults, their families and their caregivers.

## NATIONAL INDIAN COUNCIL ON AGING (NICOA)

[www.nicoa.org](http://www.nicoa.org)

The National Indian Council On Aging, Inc. (NICOA), a non-profit organization, was founded in 1976 by members of the National Tribal Chairmen's Association that called for a national organization focused on aging American Indian and Alaska Native Elders.

## SAGE: ADVOCACY & SERVICES FOR LGBTQ+ ELDERS

[www.sageusa.org](http://www.sageusa.org)

SAGE is the country's largest and oldest organization dedicated to improving the lives of LGBTQ+ older people. Founded in 1978 and headquartered in New York City, SAGE is a national organization that offers supportive services and consumer resources to LGBTQ+ older people and their caregivers.

## SOUTHEAST ASIA RESOURCE ACTION CENTER (SEARAC)

[www.searac.org](http://www.searac.org)

SEARAC is the only national civil rights organization devoted to uplifting Cambodian, Laotian, and Vietnamese American communities.

## NATIONAL RESOURCES

### AARP CAREGIVING RESOURCE CENTER

[www.aarp.org/caregiving](http://www.aarp.org/caregiving) or 877-333-5885

Your one-stop shop for tips, tools and resources while caring for a loved one. For Spanish resources visit [www.aarp.org/cuidar](http://www.aarp.org/cuidar) or call 888-971-2013.

### ADMINISTRATION ON COMMUNITY LIVING (ACL)

[www.acl.gov](http://www.acl.gov)

The federal agency responsible for advancing the concerns and interests of older people. The website has a variety of tools and information for older adults and family caregivers.

### ALZHEIMER'S ASSOCIATION

[www.alz.org](http://www.alz.org) or 800-272-3900

Resources, tools, and a 24-hour helpline for people with Alzheimer's disease and their families.

### AMERICAN CANCER SOCIETY

[www.cancer.org](http://www.cancer.org) or 800-227-2345

From basic information about cancer and its causes to in-depth information on specific cancer types— including risk factors, early detection, diagnosis and treatment options.

### AMERICAN DIABETES ASSOCIATION

[www.diabetes.org](http://www.diabetes.org) or 800-342-2383

Resources and research to prevent, cure and manage diabetes.

### AMERICAN HEART ASSOCIATION

[www.heart.org](http://www.heart.org) or 800-242-8721

Resources will help you better care for someone who has heart disease or who has had a heart attack, heart surgery or a stroke.

### CARE.COM

[www.care.com](http://www.care.com)

Improving the lives of families and caregivers by helping them connect in a reliable and easy way.

### CAREGIVER ACTION NETWORK

[www.caregiveraction.org](http://www.caregiveraction.org) or 202-454-3970

Information, educational materials and support for family caregivers.

### FAMILY CAREGIVER ALLIANCE

[www.caregiver.org](http://www.caregiver.org) or 800-445-8106

Tools and resources for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.

### NATIONAL CLEARINGHOUSE FOR LONG-TERM CARE INFORMATION

[www.longtermcare.gov](http://www.longtermcare.gov)

Information and tools to help plan for long-term care needs.

### MEDICARE

[www.medicare.gov](http://www.medicare.gov) or 800-633-4227

Provides information about the Medicare program and how to find Medicare plans and providers. Caregivers will also find a tool on the website to compare home health care agencies and nursing homes. The official U.S. government site for Medicare.

### NATIONAL ACADEMY OF ELDER LAW ATTORNEYS

[www.naela.org](http://www.naela.org)

A professional association of attorneys who specialize in legal services for older adults and people with special needs. Find information on legal issues affecting older adults and a database of elder law attorneys by state.

### NATIONAL ALLIANCE FOR CAREGIVING

[www.caregiving.org](http://www.caregiving.org)

This organization is dedicated to improving the quality of life for caregivers and those they care for through research, innovation and advocacy.

### NATIONAL ALLIANCE FOR HISPANIC HEALTH

[www.healthyamericas.org](http://www.healthyamericas.org) or 866-783-2645

The Hispanic Family Health Helpline and its Su Familia provide free and confidential health information for Hispanic/Latino families.



# Ten Things You Should Know About Language Access Advocacy for Older Adults

**1.****Approximately 5 million of America's older adults are limited English proficient ("LEP").**

This means that these individuals do not speak English as their primary language or have a limited ability to read, speak, write, or understand English.

**2.****A significant number of LEP seniors are low-income.**

In 2015, 43.8% of low-income SSI applicants who were 65 and over asked to be interviewed in a language other than English. These individuals may be legally entitled to language assistance with respect to a particular service, benefit, or encounter.

**3.****LEP seniors are diverse and live throughout the U.S.**

Hailing from many different backgrounds and ethnicities, LEP seniors are not just in coastal centers or large metropolitan areas. Minnesota is home to many Somalis. Large Hmong communities reside in towns such as La Crosse, Wisconsin. Spanish-speaking elders, who comprise the largest single LEP group, are a significant presence in almost every state. LEP seniors also speak many different languages. The Social Security Administration's Multilanguage Gateway contains Social Security information in 18 languages and includes specific instructions in all 18 languages on how to request free interpreter services.

**4.****Many LEP seniors are unable to attain full fluency in English.**

Due to age and physical barriers it is unrealistic to expect many LEP seniors to attain full proficiency. These barriers often combine with other factors to prevent seniors from attaining fluency through the typical methods such as working, going to school, or raising children. In addition, across the country, wait lists for English as a Second Language (ESL) classes number in the thousands.

**5.****Language access is a protected civil right.**

Federal law prohibits discrimination based on national origin, including discrimination on the basis of language. These civil rights protections have become well-established through an Executive Order by President Clinton in 2000 and various federal regulations. Any recipient of federal funds is required to take reasonable steps to ensure meaningful access to programs by LEP individuals. Many states and localities also have enacted additional specific requirements for language services for LEP individuals. For example, California has 12 threshold languages for its Medicaid program, and, depending on the county, the state and its contractors must provide written translation of beneficiary notices and materials.





6.

**Language assistance, including translation and interpretation, and cultural competency is vital to assist LEP seniors in navigating aging network services.**

Cultural competence, or the ability to interact effectively with persons of different cultures, is also a key component of effective communication with LEP individuals. Although it is vital that in-language interpretation and translation services are provided, cultural competency demands more: a grasp of one's own cultural worldview, holistic knowledge of different cultural practices and worldviews, and cross-cultural communication skills." (Note: "translation" refers to written materials, and interpretation is oral assistance.)

7.

**Many organizations serving LEP clients use professional "language line" services—telephonic services available in hundreds of languages on demand.**

Such services may also be able to provide "oral translation," or simultaneous spoken communication about the contents of a document written in English. Such services can be extremely effective, but must not take the place of hiring bilingual staff and providing written translations.

8.

**To be effective, language services must meet certain qualitative standards, particularly when a client's legal rights, health, or well-being is at stake.**

Trained professionals familiar with appropriate concepts and specialized vocabulary can be extremely important to avoid dangerous or detrimental outcomes. Children and family members, especially minor grandchildren, are not ideal interpreters. Untrained laypersons often are unfamiliar with legal or medical terms and can make serious mistakes, and individuals may be deterred from fully sharing symptoms or other important personal details in the presence of a family member.

9.

**As required by federal law, organizations serving LEP populations should endeavor to undergo regular assessment, planning, and monitoring of LEP outreach and the delivery of services.**

Achieving progress in gaining individual and institutional cultural competence should be seen as a dynamic, ongoing process. Look to CLAS standards for blueprints of culturally and linguistically appropriate services: [www.thinkculturalhealth.hhs.gov](http://www.thinkculturalhealth.hhs.gov).

10.

**Justice in Aging has long fought for improved language access policies on behalf of low-income older adults.**

For more resources and information on serving LEP older adults from Justice in Aging and its partners, please visit their [LEP resource page](#).

# COVID-19 Resources for Family Caregivers



## TELEPHONE HOTLINES

### AARP Fraud Prevention Helpline

During these difficult times, fraudulent calls are more common. If you suspect you are being targeted by a fraud or scam, call AARP's toll-free helpline: 877-908-3360.

### SAGE National LGBTQ+ Elder Hotline

Talk and be heard at the SAGE LGBTQ+ Elder Hotline. We connect LGBTQ+ older people who want to talk with friendly responders who are ready to listen. Responders are crisis certified. The line is open 24 hours, 7 days a week.

### National Asian Pacific Center on Aging Automated In-Language Helpline

Older adults who face barriers due to language or access to technology are able to receive assistance in through NAPCA's Helpline and website. Monday-Friday between 8:30am-1pm PT, callers are able to reach live-operators in English, Cantonese, Mandarin, Korean and Vietnamese for residents of Los Angeles and Seattle. The Helpline also offers recorded in-language guided meditations to support callers with exercises in grounding, relaxation, breathing, and gratitude. Recorded information on COVID-19

prevention, symptoms, and planning in eight different languages is also available.

The languages are listed below.

- English: 1-800-336-2722
- 廣東話 / Cantonese: 1-800-582-4218
- 普通话 / Mandarin: 1-800-683-7427
- 한국어 / Korean: 1-800-582-4259
- 日本語 / Japanese: 1-800-398-1117
- Tagalog / Filipino: 1-800-593-8087
- Tiếng Việt / Vietnamese: 1-800-582-4336
- Español / Spanish: 1-800-948-3844

### Alzheimer's Association 24/7 Helpline

24/7 Helpline (800.272.3900) is available around the clock, 365 days a year. Through this free service, specialists and master's-level clinicians offer confidential support and information to people living with the disease, caregivers, families and the public during the COVID-19 crisis.



## ADVOCATING FOR YOURSELF AND OTHERS DURING THE PANDEMIC

### Advocating for Yourself and Others: Health and Aging Services

#### Advocating for Yourself and Others: Health and Aging Services (Spanish)

Created by SAGE and the National Resource Center on LGBTQ+ Aging, This article provides useful information you can use to advocate for yourself and others in health and aging services by implementing four key actions: preparation, communication, cultivation, and documentation. This document is also available in Spanish.

### Know Your Rights Based on the Title VI of the Civil Rights Act of 1964

Title VI of the Civil Rights Act of 1964 ensures nondiscrimination in Federally Assisted Programs and States that "No person the United States shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal finance assistance.



## DAILY LIVING: GROCERIES, IN-HOME SERVICES, SOCIAL CONNECTION

### Community Resource Finder

This website was created in partnership with the Alzheimer's Association, AARP, and Carelike to provide community-based services focused on care at home services, housing options, medical services, and program and events from both AARP and the Alzheimer's Association. Community services also include skilled nursing and home care aids to provide services.

### ACL Eldercare Locator

Enter your zip code to find your local Area Agencies on Aging (AAA). Local AAAs can provide information regarding meal delivery and other services including case management, in-home services, insurance counseling, legal assistance, medical transportation, information and assistance. Along with AAAs, American Indian and Alaska Natives can also find Title VI programs through the Eldercare Locator.

### SAGEConnect

SAGEConnect links LGBTQ+ elders with their broader community, reducing isolation and promoting well-being. If you know someone who would benefit from SAGEConnect, but doesn't have internet, call the registration line at 929-484-4160.

### Where to Get Food Help Now—National Council on Aging

Affording healthy food is a challenge for many older Americans, but the spread of COVID-19 has made matters worse. Whether you're facing difficult financial times or are unable to leave your home, there are resources that may be able to help.



## INFORMATIONAL PRINT MATERIALS AND FACT SHEETS

### SEARAC COVID-19 Rapid Response Guide

This guide has information and in-language fact sheets focused on Southeast Asian American languages such as Cambodian/Khmer, Hmong, Laotian, and Vietnamese.

### Fact Sheets for Tribes and Urban Indian Communities

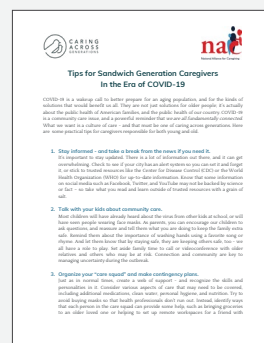
These resources focus on the impact COVID-19 has across Indian Country including tribes, Urban Indian Health Programs, and urban Indian communities.

### Caregiver Tip Sheets from Alzheimer's LA

Printable tip sheets for family caregivers, available in English, Spanish, Japanese, and Chinese, on topics such as Anxiety, Medications, Sleeping and more.

### Tips for Sandwich Generation Caregivers in the Era of COVID-19

COVID-19 is a wakeup call to better prepare for an aging population, and for the kinds of solutions that would benefit us all. They are not just solutions for older people; it's actually about the public health of American families, and the public health of our country. COVID-19 is a community care issue, and a powerful reminder that we are all fundamentally connected. What we want is a culture of care—and that must be one of caring across generations. Here are some practical tips for caregivers responsible for both young and old.







## RESOURCES FOR FAMILY CAREGIVERS

### Caregiver Action Network— Caregiver Help Desk

Contact our Care Support Team, staffed by caregiving experts, to help you find the right information you need to help you navigate your complex caregiving challenges. Caregiving experts are available 8:00 AM – 7:00 PM ET by phone, email, and online chat.

### Apart, Not Alone—A Guide for Remote Caregiving During COVID-19

APART NOT ALONE goes in-depth into the necessities of remotely providing care during COVID-19. The first section, Health & Safety, covers Preparation, Health and Safety Best Practices, and guidance for securing Medical Care. The second section, The Essentials, spans Shopping and Meals; Social Connections via Technology; and vitality, Cognitive Stimulation, Exercise, and Emotional Support.

### COVID-19 Respite and Caregiving Resources

The National Respite Locator Service helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs, including support programs, adult day services, and informal connections.

### Video Series from UnidosUS: Explaining COVID-19 Relief for Latino Families

The CARES Act, the Coronavirus Aid, Relief and Economic Security Act, is a relief package passed by Congress in March. In the video series “UnidosUS CARES: Explaining COVID-19 Relief for Latino Families” we talk about what this package includes and what it means for the Latino community from the health, education, jobs and housing, and immigration perspectives. We also cover what is missing and what needs to be done.



## TRANSLATED INFORMATIONAL FACT SHEETS

### Elder Mental Health in the time of COVID-19 (Spanish)

### Elder Mental Health in Time of COVID-19 (English)

This informational article produced by NHCOA is available in both English and Spanish. The article provides more information on COVID-19 and the importance of mental health for older adults during these difficult times.

### Myths and Rumors about COVID-19 (Spanish)

### Myths and Rumors about COVID-19 (Portuguese)

### Myths and Rumors about COVID-19 (English)

Produced by NHCOA this informational article does a great job in debunking myths and rumors about COVID-19 such as the use of garlic and how temperature affects the virus among many other myths and rumors. Check it out!

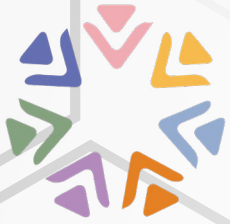
### COVID-19, CDC Recommends Use of Masks in Public Settings (Spanish)

### COVID-19, CDC Recommends Use of Masks in Public Settings (English)

Written by NHCOA, this article elaborates on the importance of face mask wearing amid the COVID-19 pandemic. The article also elaborates on the research behind face mask wearing, other things to consider while wearing face masks and other useful strategies for COVID-19 prevention.







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 [diverseelders.org/caregiving](https://diverseelders.org/caregiving)

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