



# 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 lesbian, gay, bisexual, transgender and/or queer/questioning (LGBTQ+) 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, transgender and queer/questioning (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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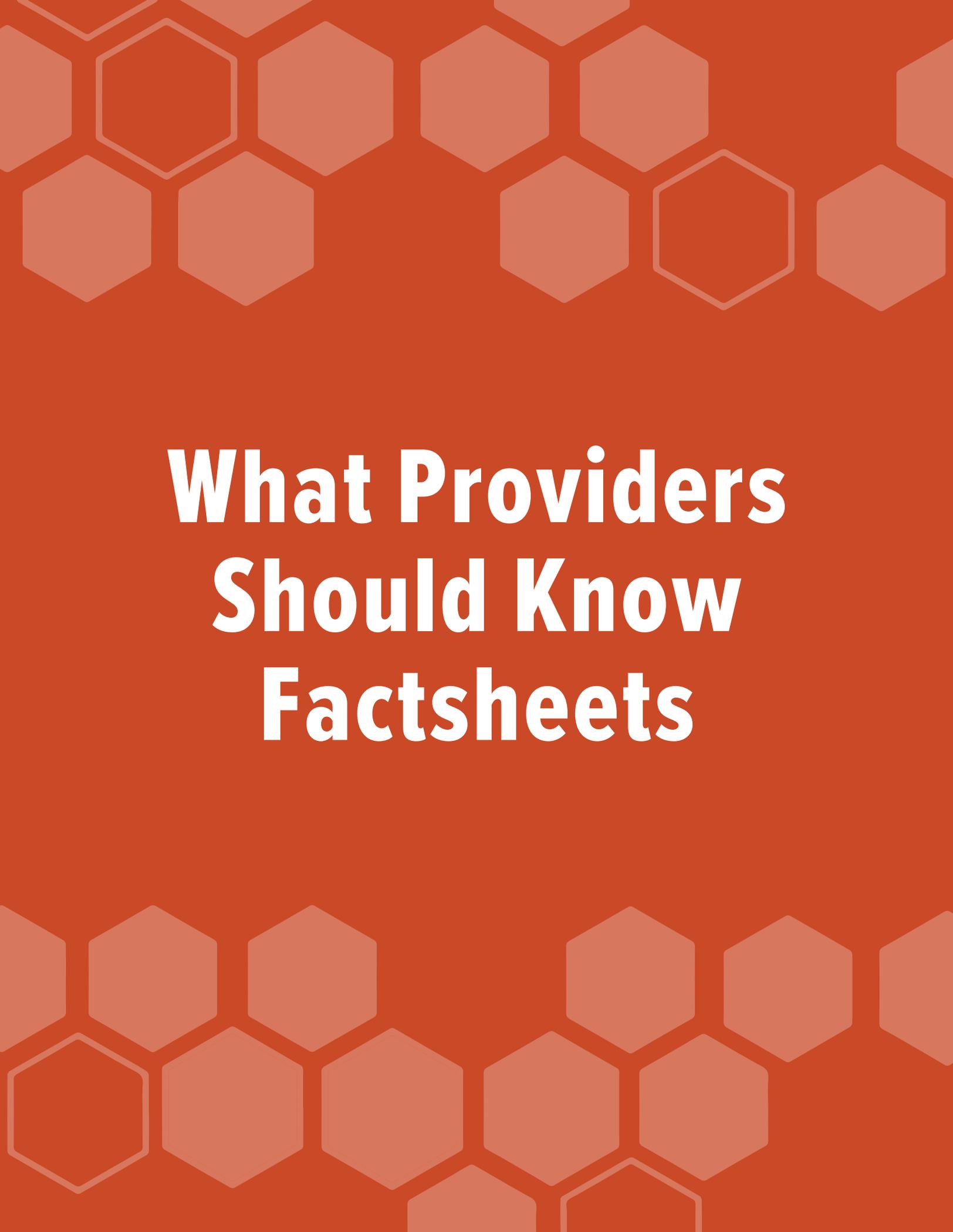
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# **What Providers Should Know Factsheets**

# 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

## Lo que los proveedores deben saber sobre los cuidadores familiares afroamericanos y de raza negra



### No existe una etnia, cultura, idioma y/o experiencia uniforme entre quienes se identifican como afroamericanos/de raza negra.

(Kusow, 2014)

- Existen distinciones dentro de “afroamericano” y entre “afroamericano” y “de raza negra” que tienen un significado cultural y lingüístico.
  - Una persona nacida en EE. UU. con ascendencia africana se considera afroamericana
  - La mayoría de los inmigrantes africanos se identifican con sus respectivas etnias de origen
  - Los afrocubanos, los afrocaribeños, los afrobrasileños, los afrohaitianos y los afrolatinos pueden identificarse o no con el término “afroamericano”

### DISPARIDADES MÉDICAS

- Las personas afroamericanas y de raza negra tienen mayor riesgo de padecer enfermedades cardíacas, accidentes cerebrovasculares, presión arterial alta, enfermedad de Alzheimer/demencia y diabetes.
- Los cuidadores afroamericanos y de raza negra tienen más probabilidades de cuidar a alguien que padece una afección física crónica o prolongada (NAC, AARP, 2015).
- En medio de las disparidades médicas y socioeconómicas, las familias afroamericanas/de raza negra siguen siendo resilientes.
  - Tasas más elevadas de abuelos cuidadores (Tang et al., 2015)
  - Estructuras familiares complejas
  - Múltiples cuidadores
  - **Familismo:** definido como una estructura social en la que las necesidades de la familia son más importantes y tienen prioridad sobre las necesidades de cualquier miembro de la familia

### COMPROMISO CULTURAL CON LOS CUIDADOS

- Los cuidadores afroamericanos/de raza negra declararon que “cuidar de familiares enfermos o discapacitados se consideraba una responsabilidad” (Scharlach et al., 2006) y que:
  - cumplían las normas culturales;
  - mantenían la continuidad cultural;
  - fortalecían los lazos familiares.
- En promedio, los cuidadores afroamericanos/de raza negra están de acuerdo en que la obligación cultural es una de las razones por las que brindan cuidados. Sin embargo, esto puede acarrear desafíos.
  - Los cuidadores afroamericanos/de raza negra tenían más probabilidades de ser mujeres, más jóvenes y de estar “atrapados” al cuidar a más de una persona (NAC, AARP, 2015)
  - Los abuelos cuidadores son desproporcionadamente mujeres, más jóvenes, con menos estudios y viven en la pobreza, lo que representa una población muy vulnerable (Minkler et al., 2005)
  - Es más probable que utilicen redes de apoyo informales, como organizaciones religiosas



## EN NUESTRA ENCUESTA A CUIDADORES FAMILIARES AFROAMERICANOS Y NEGROS:

**54%** declararon que tienen algunas o muchas dificultades con tareas de salud como la administración de medicamentos o el cuidado de heridas

**56%** declararon que tienen algunas o muchas dificultades para coordinar o concertar los servicios de atención de médicos, enfermeras, trabajadores sociales, etc.

**34%** están de acuerdo en que son los únicos disponibles para brindarle cuidados a un cliente

**31%** están de acuerdo en que el servicio de cuidados tuvo efectos negativos en su salud física/emocional

**31%** están de acuerdo en que se sienten aislados debido a los servicios de cuidados

 Una necesidad de servicios formales de apoyo culturalmente competentes

 Menos tiempo personal, participación limitada en otras actividades, más estrés y presión

## ¿CÓMO LOS PROVEEDORES PUEDEN APOYAR MEJOR A LOS CUIDADORES FAMILIARES AFROAMERICANOS Y DE RAZA NEGRA?

- **Reclutar, fomentar y apoyar una fuerza de trabajo interdisciplinaria diversa que comprenda/represente la cultura de la comunidad**
  - Facilitar la comunicación entre los administradores de casos del hospital y los enlaces domiciliarios
  - Más oportunidades para identificar a los cuidadores y para impartir una capacitación eficaz en materia de cuidados
- **Desarrollo de materiales cultural y lingüísticamente competentes en el consultorio para ofrecer información como la administración de medicamentos y la capacitación de cuidadores**
  - Garantizar que los materiales estén escritos a un nivel de lectura de 5.º grado o inferior
  - Incluir imágenes que reflejen a los adultos mayores afroamericanos y a sus familias
- **Identificar e incluir a los familiares pertinentes en la planificación de los cuidados centrados en la persona**
  - Revisar los formularios demográficos de los pacientes y/o los formularios de antecedentes de los adultos para identificar si un paciente está brindándole cuidados a un amigo o a un familiar
  - Ampliar la definición de “familia” de su organización para incluir a amigos, vecinos y otras personas ajenas a la estructura familiar tradicional
- **Utilizar los modos tradicionales de contacto/divulgación para identificar y fomentar servicios de apoyo, educación y capacitación (AARP, 2018; Navaie, 2011)**
  - Reuniones en persona
  - Teléfono
  - Material impreso (entregado por correo postal)
  - Boletín informativo

# 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.**

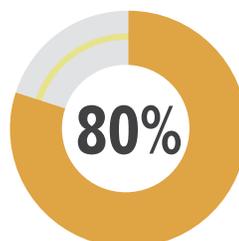
- **Tribal/Self Governance is essential to American Indian/Alaska Native culture. Tribal governments are responsible for a broad array of services, including:**
  - Education
  - Law Enforcement
  - Judicial Systems
  - Healthcare
- **Family is the center unit of American Indian/Alaska Native culture. 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

## Lo que los proveedores deben saber sobre los cuidadores familiares nativos americanos y de Alaska



**Hay 574 tribus de nativos americanos y de Alaska reconocidas a nivel federal. Cada tribu tiene su propia nación dentro de una nación mayor, independientemente de las fronteras nacionales y estatales.**

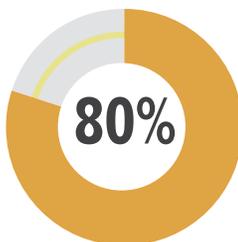
- **El gobierno tribal/autogobierno es esencial para la cultura de los nativos americanos y de Alaska. Los gobiernos tribales son responsables de una amplia gama de servicios, entre los que se incluyen:**
  - Educación
  - Sistemas judiciales
  - Cumplimiento de la ley
  - Asistencia médica
- **La familia es la unidad central de la cultura nativa americana y de Alaska. Cuidar de la familia forma parte de los valores tradicionales, y los adultos mayores gozan de gran estima entre las estructuras familiares y en la sociedad (Scharlach et al., 2006; pág. 139-140).**

### DISPARIDADES MÉDICAS

- **Las enfermedades del corazón, el cáncer y la diabetes son las principales causas de fallecimiento entre los nativos americanos y de Alaska.**
  - Los nativos americanos y de Alaska tienen el doble de probabilidades de padecer diabetes en comparación con las personas de raza blanca (CDC, 2017)
  - La diabetes es un factor de riesgo importante para las enfermedades del corazón, y es la principal causa de fallecimiento
  - Los tipos más comunes de cáncer incluyen el de próstata, mama, pulmón, colon y riñón
- **Las comunidades tribales rurales están geográficamente aisladas de los servicios y recursos de cuidados.**
  - Esto exacerba las desigualdades médicas
  - Se observa la falta de capacitación de los cuidadores

### COMPROMISO CULTURAL CON LOS CUIDADOS

- **Muchos nativos americanos y de Alaska expresan desconfianza hacia la cultura y el gobierno mayoritarios debido a una historia de pobreza, desplazamiento y discriminación. Como consecuencia, los cuidadores son más reacios a utilizar los servicios de apoyo formales (Scharlach et al., 2006).**
- **Los nativos americanos y de Alaska suelen sentir un fuerte compromiso cultural con el servicio de cuidados, y una dependencia de la familia y la tribu para obtener apoyo.**
  - Servicios de atención médica prestados por proveedores de salud tribales
  - Representantes de salud comunitaria a través de los servicios de salud nativos
  - Organizaciones comunitarias tribales locales
- **En promedio, los cuidadores nativos americanos y de Alaska están de acuerdo en que una de las razones por las que brindan cuidados es la obligación cultural.**



**DE LOS CUIDADORES NATIVOS AMERICANOS Y DE ALASKA ESTÁN DE ACUERDO O MUY DE ACUERDO EN QUE UNA DE LAS RAZONES POR LAS QUE BRINDAN CUIDADOS ES EL COMPROMISO CULTURAL.**



### EN NUESTRA ENCUESTA A CUIDADORES FAMILIARES NATIVOS AMERICANOS Y DE ALASKA:



coinciden en que son los únicos que ayudan a sus clientes de cuidados



declararon que 0 familiares, amigos o vecinos les asistieron, ayudaron o apoyaron



indican haber pagado gastos relacionados con las afecciones de salud o las discapacidades de sus familiares o amigos



declararon que tienen algunas o muchas dificultades con tareas de salud como la administración de medicamentos o el cuidado de heridas



declararon que tienen algunas o muchas dificultades para coordinar o concertar los servicios de atención de médicos, enfermeras y trabajadores sociales



Uno de cada cinco encuestados afirma que sus médicos u otros proveedores de atención médica desconocían los cuidados que les brindaban a otras personas



Son más propensos a pagar los gastos del servicio de cuidados que los cuidadores afroamericanos y de raza negra, asiáticos, oriundos del sudeste asiático o hispanos/latinos

### ¿CÓMO LOS PROVEEDORES PUEDEN APOYAR MEJOR A LOS CUIDADORES FAMILIARES NATIVOS AMERICANOS Y DE ALASKA?

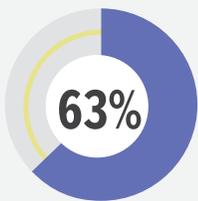
- **Para atender a los cuidadores nativos americanos y de Alaska, es necesario ser conscientes de sus raíces y sus problemas sociales, históricos, culturales, económicos y ambientales**
  - Fortalecer las organizaciones tribales y comunitarias para aumentar la capacidad de programación
  - Dedicación “compartida” en lugar de “reinventar la rueda”
- **Establecer relaciones con las comunidades tribales de su región. Esto puede incluir el desarrollo de relaciones individuales con los líderes tribales, los adultos mayores, el representante comunitario de salud y los miembros de las tribus.**
- **Desarrollar material cultural y lingüísticamente competente para la capacitación, la información sobre los servicios de cuidados, la información sobre enfermedades y la divulgación de las intervenciones**
  - Evitar palabras como “carga para el cuidador”
  - Nivel de lectura de 6.º grado o inferior
  - Utilizar imágenes que representen a nativos americanos y de Alaska
- **Consultar con los líderes tribales locales, los adultos mayores y las instituciones locales en las comunidades tribales locales para difundir material impreso y desarrollar o aumentar la capacidad de programación**
  - Aumentar la visibilidad del material impreso para reducir el estigma, proporcionar información sobre la enfermedad y capacitar/informar a los cuidadores
  - Los líderes tribales y los adultos mayores son el punto central de las comunidades tribales

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

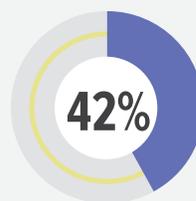


The umbrella group “Asian American and Pacific Islander” or AAPI consists of more than 50 different ethnicities with over 100 languages spoken.

- 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 American 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 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 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 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

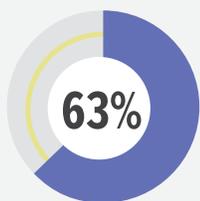
**FOREIGN-BORN CAREGIVERS IN THE US ARE OLDER, HAVE LOWER EDUCATIONAL DEGREES, LOWER INCOME, AND ASSIST MORE WITH CULTURE-RELATED TASKS, LIKE TRANSLATING HEALTHCARE INFORMATION FROM ENGLISH.**

# Lo que los proveedores deben saber sobre los cuidadores familiares sinoestadounidenses y coreanoestadounidenses

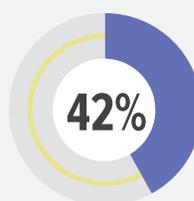


El grupo general “asiaticoamericano e isleño del Pacífico”, o AAPI (por sus siglas en inglés), está formado por más de 50 etnias diferentes con más de 100 idiomas hablados.

- Los chinos son el mayor grupo étnico asiaticoamericano de 55 años o más (NAPCA, 2013).



DE LA POBLACIÓN CHINA NACIÓ EN EL EXTRANJERO (PEW, 2015)



DE LA POBLACIÓN NACIDA EN EL EXTRANJERO TIENE 50 AÑOS O MÁS

## DISPARIDADES MÉDICAS

- Históricamente, las comunidades AAPI se han enfrentado a importantes barreras para acceder a un seguro médico asequible y a servicios de salud de calidad, y estas barreras han contribuido a las disparidades médicas.**
  - Es probable que las comunidades asiaticoamericanas, nativas de Hawái y de otras islas del Pacífico carezcan de cobertura de seguro médico
  - Las afecciones de salud que son comunes en la comunidad AAPI, como la diabetes, la obesidad, el cáncer, el VIH/SIDA y las enfermedades mentales, a menudo no se diagnostican ni se tratan (WHIAAPI).

## COMPROMISO CULTURAL CON LOS CUIDADOS

- En promedio, los cuidadores sinoestadounidenses coinciden en que la obligación cultural es una de las razones por las que le brindan cuidados a un familiar o amigo.**
- Es más probable que los cuidadores de la población AAPI adopten o estén influenciados por las expectativas relacionadas con el concepto de piedad filial (virtud del respeto, el cuidado y la obediencia).**
- Los cuidadores familiares sinoestadounidenses y coreanoestadounidenses declararon que, al cuidar a familiares enfermos o discapacitados (Scharlach et al., 2006):**
  - cumplían las normas culturales;
  - mantenían la continuidad cultural;
  - fortalecían los lazos familiares.

## ¿CÓMO LOS PROVEEDORES PUEDEN APOYAR MEJOR A LOS CUIDADORES FAMILIARES SINOESTADOUNIDENSES Y COREANOESTADOUNIDENSES?

- Utilizar intérpretes médicos capacitados y culturalmente competentes cuando hablen con cuidadores familiares AAPI**
  - Los pacientes con dominio limitado del inglés tenían 27 % más probabilidades de ser readmitidos (Diamond et al., 2017)
- Evaluar la dificultad con las tareas culturales en la selección de cuidadores y pacientes**
  - Los cuidadores que declararon tener grandes dificultades con las tareas culturales tuvieron peores resultados de salud
  - Editar las herramientas de evaluación de la carga para el cuidador, a fin de recopilar información sobre las responsabilidades del servicio de cuidados



## EN NUESTRA ENCUESTA A CUIDADORES FAMILIARES SINOESTADOUNIDENSES Y COREANOESTADOUNIDENSES:



declararon que tienen algunas o muchas dificultades para ayudar en tareas culturales, como:

- superar las barreras lingüísticas al hablar con los proveedores de atención médica o de servicios;
- traducir información relacionada con la salud al idioma principal;
- problemas legales relacionados con trámites de inmigración o naturalización.



declararon que tienen algunas o muchas dificultades con tareas de salud como la administración de medicamentos y el cuidado de heridas



declararon que tienen algunas o muchas dificultades para coordinar o concertar los servicios de atención de médicos, enfermeras, trabajadores sociales, etc.



de los cuidadores coreanoestadounidenses estuvieron de acuerdo o muy de acuerdo en que el servicio de cuidados tuvo efectos negativos en su salud emocional



Los cuidadores que declararon tener más dificultades para realizar tareas culturales:

- tienen niveles más altos de los cuatro tipos de tensión y depresión del cuidador;
- dieron valoraciones más bajas a la calidad de la atención médica prestada a sus clientes;
- declararon sentirse menos satisfechos con el apoyo de sus familiares o amigos.

## ¿CÓMO LOS PROVEEDORES PUEDEN APOYAR MEJOR A LOS CUIDADORES FAMILIARES SINOESTADOUNIDENSES Y COREANOESTADOUNIDENSES?

(Continuación)

### ● Desarrollar materiales traducidos para tener conocimiento de la enfermedad, los tratamientos y la capacitación

- Los materiales en el consultorio ayudan a mitigar las escasas oportunidades de hablar con los proveedores por falta de tiempo
- Los adultos mayores de la población AAPI consideran que los materiales en el consultorio son los más impactantes a la hora de proporcionar información relacionada con la salud (AARP, 2018)

### ● Proporcionar remisiones y recursos culturalmente competentes

- Difusión de material culturalmente competente en el consultorio para capacitar e informar
- Remisiones asequibles y en su idioma

### ● Desarrollar grupos de apoyo a cuidadores en su idioma

- Resolver el aislamiento social y lingüístico
- Proporcionar una red de apoyo a los cuidadores de adultos mayores con bajo nivel de inglés (LEP, por sus siglas en inglés)

### ● Desarrollar talleres de educación/capacitación de cuidadores en su idioma

- Anuncios y materiales que reflejen a los adultos mayores y a los cuidadores de la población AAPI
- Asegurarse de que los materiales se traducen tanto lingüística como culturalmente

LOS CUIDADORES EN EE. UU. QUE NACIERON EN EL EXTRANJERO SON MAYORES, TIENEN UN NIVEL EDUCATIVO INFERIOR, OBTIENEN MENOS INGRESOS Y AYUDAN MÁS EN TAREAS RELACIONADAS CON LA CULTURA, COMO TRADUCIR LA INFORMACIÓN DEL INGLÉS SOBRE LA ASISTENCIA MÉDICA.

# 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:



51% agree that they are the only person available to provide care to their care recipients



36% report some or a great deal of difficulty assisting with cultural tasks, such as translating health information into their native language



25% 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

# Lo que los proveedores deben saber sobre los cuidadores familiares estadounidenses oriundos del sudeste asiático



Los estadounidenses oriundos del sudeste asiático (SEAA, por sus siglas en inglés) son una identidad política y racial de un subgrupo de asiaticoestadounidenses que se reasentaron principalmente en Estados Unidos como refugiados durante la década de los setenta. Esta denominación incluye a:

## Cham

UN GRUPO MINORITARIO MUSULMÁN

## Iu Mien

O MIEN

## Jemer Kampuchea Krom

O ETNIA JEMER

## Jemer

## Khmu

## Jemer Loeu

O JEMER DE LAS TIERRAS ALTAS

## Lao

O LAO LOUM/LAO DE LAS TIERRAS BAJAS

## Montagnards

O MONTAÑESES DE VARIAS ETNIAS DIFERENTES

## Hmong

## Taidam

## Vietnamitas

\* CIERTAS ETNIAS CHINAS TAMBIÉN TIENEN RAÍCES EN CAMBOYA, LAOS Y VIETNAM.

## DISPARIDADES MÉDICAS

- Las tasas de dominio limitado del inglés en las comunidades estadounidenses oriundas del sudeste asiático se sitúan entre el 40 y el 50 %. En el caso de los adultos mayores, esas cifras pueden llegar al 90 %.
- Los SEAA se ven afectados por los traumas de la guerra y el reasentamiento, el bajo nivel socioeconómico y las recientes deportaciones masivas.
  - Acceso inadecuado a los servicios de salud mental
  - Hijos adultos apartados de la estructura de cuidadores familiares
  - Fomenta la desconfianza hacia cualquier servicio formal
- Las tasas de pobreza en todos los grupos étnicos del SEAA están por encima de del promedio nacional (11.3 %).
  - Hmong 27.4 %
  - Camboyanos 18.2 %
  - Vietnamitas 13 %
  - Laosianos 12.2 %

## COMPROMISO CULTURAL CON LOS CUIDADOS

- La familia y el respeto son dos pilares de los valores tradicionales vietnamitas.
- Los cuidadores vietnamitas declararon que, al cuidar a familiares enfermos o discapacitados (Scharlach et al., 2006):
  - cumplían las normas culturales;
  - mantenían la continuidad cultural;
  - fortalecían los lazos familiares.
- En promedio, los cuidadores SEAA coinciden en que la obligación cultural es una de las razones por las que le brindan cuidados a un familiar o amigo.

ALREDEDOR DE 1.1 MILLONES DE ASIÁTICOS DEL SUDESTE FUERON REASENTADOS DURANTE LA GUERRA DE VIETNAM Y EL GENOCIDIO CAMBOYANO. EL INADECUADO APOYO AL REASENTAMIENTO A SU LLEGADA SUPUSO MUCHAS BARRERAS PARA LOS SEAA, ENTRE ELLAS LAS ALTAS TASAS DE DOMINIO LIMITADO DEL INGLÉS.



## EN NUESTRA ENCUESTA A CUIDADORES FAMILIARES ESTADOUNIDENSES ORIUNDOS DEL SUDESTE ASIÁTICO:

51%

están de acuerdo en que son los únicos disponibles para brindarles cuidados a sus clientes

36%

declararon que tienen algunas o muchas dificultades para ayudar en tareas culturales, como la traducción de la información de salud a su idioma nativo

25%

declararon que sus proveedores de atención médica no conocían los cuidados que les brindaban a sus seres queridos



Una cuarta parte de los encuestados está de acuerdo en que el servicio de cuidados tuvo efectos negativos en su salud física/emocional

- Menos tiempo personal, participación limitada en otras actividades, más estrés y presión
- El **22.7 %** está de acuerdo en que se sienten aislados debido a los servicios de cuidados
- El **14.3 %** declaró sentir más síntomas de depresión a veces o a menudo

## ¿CÓMO LOS PROVEEDORES PUEDEN APOYAR MEJOR A LOS CUIDADORES FAMILIARES ESTADOUNIDENSES ORIUNDOS DEL SUDESTE ASIÁTICO?

- **Utilizar intérpretes médicos capacitados y culturalmente competentes cuando hablen con cuidadores familiares estadounidenses oriundos del sudeste asiático**
- **Evaluar la dificultad con las tareas culturales en la selección de cuidadores y pacientes**
  - Los cuidadores que declararon tener grandes dificultades con las tareas culturales tuvieron peores resultados de salud que los pacientes que declararon tener pocas dificultades
- **Desarrollar materiales traducidos y culturalmente competentes en el consultorio para tener conocimiento de la enfermedad, los tratamientos, la divulgación y la capacitación**
  - Reducción del estigma que rodea a las enfermedades
  - Menores tasas de readmisión
  - Mayor satisfacción de los cuidadores
- **Crear colaboraciones y proporcionar financiación/apoyo a las organizaciones comunitarias que prestan servicios a las comunidades SEAA**
- **Desglosar los datos que se recogen en los formularios de ingreso y en los entornos médicos**
  - Mejor comprensión de los desafíos y las fortalezas propios de las comunidades SEAA
- **Proporcionar remisiones y recursos culturalmente competentes para resolver las dificultades considerables con las tareas culturales**
- **Desarrollo de grupos de apoyo a cuidadores en su idioma**
  - Casi la mitad de los cuidadores de SEAA indican ser los únicos disponibles para brindar cuidados
  - Mejorar la salud mental y reducir el aislamiento
  - Crear un lugar seguro para compartir preocupaciones y aprender de los demás
  - Mejores resultados para los cuidadores

# What Providers Should Know About Hispanic and Latino Family Caregivers



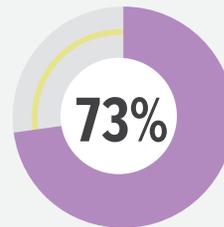
The Hispanic/Latino community is the largest ethnic minority group in the US, comprising 18.1% of the total US population.

(Census, 2018)

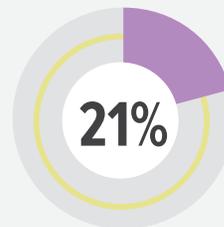
● **Culture and language have a big impact on access to care and supports.**

- 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

## Cuidadores familiares hispanos/latinos



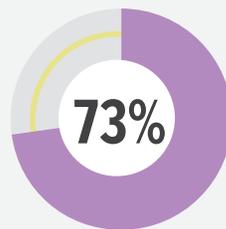
La comunidad hispana es el grupo étnico minoritario más grande de los Estados Unidos, comprendiendo el 18.1% de la población total de los Estados Unidos.

(Censo, 2018)

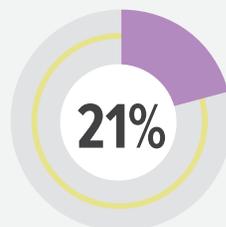
● **La cultura y el idioma tienen un gran impacto en el acceso a la atención y apoyos.**

- Es más probable que confíen en la familia y menos probable que busquen recursos externos (Flores et al, 2009)
- Los cuidadores familiares hispanos/latinos de habla hispana informan que se sienten poco preparados, lo que resulta en el aislamiento y la separación de la vida social (AARP)

● **Realmente no hay una buena palabra para “cuidador en español”. La palabra “cuidador” se utiliza a veces, pero no resuena con muchos hispanos y latinos. (NHCOA)**



EL 73% DE LOS HOGARES HISPANOS DE ESTADOS UNIDOS HABLAN ESPAÑOL EN CASA (PEW, 2017)



1 DE CADA 5 ESTADOUNIDENSES ADULTOS MAYORES SERÁ HISPANO/LATINO PARA 2060 (ACL, 2017)

### COMPROMISO CULTURAL CON EL CUIDADO

● **El familismo: un valor cultural central de los latinos. Implica dedicación, compromiso y lealtad a la familia. Pasar regularmente tiempo con la familia inmediata y extendida es parte del familismo. También implica buscar el consejo de la familia para las decisiones importantes.**

● **Las familias hispanas tienden a adoptar o ser impactadas por el valor del familismo. (McClearly, 2013)**

- El 27% de los hispanos/latinos que viven en los Estados Unidos viven en hogares familiares multigeneracionales.
- El cuidado se describe como “algo que simplemente hay que hacer”, y no como lo “correcto” que hay que hacer”

### EN NUESTRA ENCUESTA A LOS CUIDADORES FAMILIARES HISPANOS:



informa que tiene alguna o mucha dificultad con las tareas de cuidado personal y de atención médica, como el manejo de los medicamentos y el cuidado de las heridas



informa que tiene alguna o mucha dificultad para coordinar la atención o los servicios de médicos, enfermeras, trabajadores sociales u otros profesionales



afirma tener alguna o mucha dificultad con las tareas culturales, como, por ejemplo hablar con los proveedores de atención de servicios



## ¿CÓMO PUEDEN LOS PROVEEDORES APOYAR MEJOR A LOS CUIDADORES FAMILIARES HISPANOS?

- **Reclutar, promover y apoyar una fuerza laboral diversa que entienda/represente la cultura de la comunidad**
  - La representación cultural entre los proveedores es importante para los cuidadores hispanos/latinos y los adultos mayores (Terlizzi et al., 2019)
  - Comunicación más fácil, mejores resultados para el paciente y el cuidador
- **Utilizar intérpretes médicos capacitados y culturalmente competentes al hablar con los cuidadores familiares hispanos/latinos y los adultos mayores**
- **Evaluar la dificultad de las tareas culturales en la selección del cuidador y del paciente**
  - Los cuidadores que informaron de una alta dificultad con las tareas culturales tuvieron más resultados de salud deficientes que los pacientes que informaron de una baja dificultad
- **Asociarse con organizaciones comunitarias para proporcionar referencias y recursos culturalmente competentes**
- **Desarrollar material traducido y culturalmente competente en la oficina para proporcionar información y formación**
- **Utilizar a los líderes de la comunidad para reclutar y ofrecer una programación integral e innovadora entre los adultos mayores hispanos/latinos y sus cuidadores**
  - El conocimiento del entorno como indicador de la utilización de servicios formales (Starrett, 1990)
  - Oportunidad de proporcionar información sobre el estigma de las diferentes enfermedades.
- **Desarrollo de grupos de apoyo para cuidadores en su idioma**
  - Puede llevar a mejorar los resultados de los cuidadores
  - Oportunidad de ofrecer talleres de formación para cuidadores

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



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

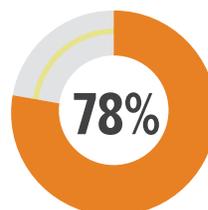
- **Being gay was a mental illness until the 1980s. Marriage equality just happened in 2015. Older adults have had not an experience of tolerance—theirs has been an experience of survival.**
- **Family of Choice:** many LGBTQ+ people become estranged from their biological families because of their LGBTQ+ 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**

# Lo que los proveedores deben saber sobre los cuidadores familiares lesbianas, gays, bisexuales, transgénero y queer/en cuestionamiento (LGBTQ+)



## Los cuidadores familiares lesbianas, gays, bisexuales, transgénero y queer/en cuestionamiento (LGBTQ+) tienen desafíos y fortalezas propios de sus identidades.

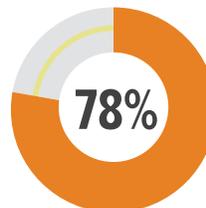
- Ser gay era una enfermedad mental hasta la década de los ochenta. El matrimonio igualitario se logró apenas en el 2015. Los adultos mayores no han tenido una experiencia de tolerancia; la suya ha sido una experiencia de supervivencia.
- **Familia de elección:** muchas personas LGBTQ+ se alejan de sus familias biológicas debido a sus identidades LGBTQ+, y en su lugar crean “familias de elección” a partir de amigos, compañeros y vecinos. En muchos casos, estas son las personas que les brindan cuidados a los miembros de la comunidad LGBTQ+, que tienen menos probabilidades de estar casados y de tener hijos, y más probabilidades de vivir solos.

### COMPROMISO CULTURAL CON LOS CUIDADOS

- Muchas personas que se identifican como LGBTQ+ confían en familias de elección para que les brinden cuidados.
  - Es cuatro veces menos probable que tengan hijos y dos veces más probable que sean solteros
  - Las familias de elección no suelen estar reconocidas por los servicios formales
- Los adultos LGBTQ+ se convierten en cuidadores a un ritmo mucho mayor que la población general de cuidadores (AARP & National Alliance for Caregiving, 2015).
  - Los cuidadores LGBTQ+ representan alrededor del 9 % de la población de cuidadores
  - Esta cifra podría ser mayor, ya que algunas personas pueden tener miedo a revelar su sexualidad debido a la discriminación

### DISPARIDADES MÉDICAS

- Los cuidadores que se identifican como una minoría sexual y/o de género declararon ser discriminados por los proveedores de atención médica y los sistemas de salud burocráticos (Fredriksen-Golden, Jen, Bryan y Goldsen, 2016).
  - Tienen dudas a la hora de acudir a los servicios y buscar orientación en materia de cuidados
  - Dependen más del apoyo de familiares, amigos y vecinos
- Las personas transgénero sufren una discriminación generalizada en la atención médica, el empleo y la vivienda (Bradford et al., 2013).
- Debido a los antecedentes de discriminación y a las barreras en la atención médica mencionadas (familia de elección), es posible que los cuidadores y los clientes LGBTQ+ no obtengan la información, la educación, la capacitación y otros recursos necesarios para brindar cuidados sostenibles y de alta calidad.



EL 78 % DE LOS ADULTOS MAYORES LGBTQ+ OCULTAN SU SEXUALIDAD AL INGRESAR A UN ASILO PARA ADULTOS MAYORES O UN CENTRO DE VIDA ASISTIDA.



## EN NUESTRA ENCUESTA A CUIDADORES FAMILIARES LGBTQ+:

**43%** declararon que tienen algunas o muchas dificultades con tareas de salud como la administración de medicamentos o el cuidado de heridas

**63%** declararon que tienen algunas o muchas dificultades para coordinar o concertar los servicios de atención de médicos, enfermeras, trabajadores sociales, etc.

**37%** Más de una cuarta parte acepta sentirse aislados debido a los servicios de cuidados

- Menos tiempo personal, participación limitada en otras actividades, más estrés y presión
- Mayor incidencia de aislamiento que otros grupos

 **Es más probable que los cuidadores LGBTQ+ declaren sentirse los únicos disponibles para brindar cuidados en comparación con otros grupos diversos**

- El 45 % está de acuerdo en que son los únicos disponibles para brindar cuidados
- Otros familiares pueden hacer suposiciones injustas de que la persona LGBTQ+ “no tiene pareja ni hijos” y, por lo tanto, tiene tiempo para cuidar a un adulto mayor

 **Es menos probable que los cuidadores LGBTQ+ busquen ayuda porque temen ser discriminados**

## ¿CÓMO LOS PROVEEDORES PUEDEN APOYAR MEJOR A LOS CUIDADORES FAMILIARES LGBTQ+?

- **Recopilar información sobre la identidad de género y la orientación sexual para comprender mejor las necesidades de sus pacientes y cuidadores**
  - Modificar las herramientas demográficas de adquisición y documentación de información sobre la orientación sexual y la identidad de género
  - Reflejar las palabras que utilizan las personas para describir sus identidades y relaciones
- **Proporcionar remisiones y recursos culturalmente competentes**
- **Desarrollar y aprovechar las alianzas con organizaciones comunitarias locales (CBO, por sus siglas en inglés) para remitir a los cuidadores a grupos de capacitación y apoyo adaptados al colectivo LGBTQ+**
- **Crear entornos de apoyo acogedores y seguros para cuidadores LGBTQ+ y adultos mayores**
  - Utilizar carteles, señales, la bandera del arcoíris en la puerta principal para darles la bienvenida a los adultos LGBTQ+, pero solo después de una capacitación y una auditoría de las políticas para garantizar que los servicios son acogedores
  - Eliminar el miedo al prejuicio, la discriminación y el rechazo
  - Capacitar continuamente al personal en aptitudes LGBTQ+
  - Desarrollar anuncios, folletos y panfletos culturalmente competentes y que reflejen a los miembros LGBTQ+
- **Desarrollar programas para incluir a los adultos mayores y/o a los cuidadores LGBTQ+**
- **Asegurarse de que las políticas de no discriminación de su organización incluyan la orientación sexual y la identidad de género, y que cualquier uso de la palabra “familia” deje claro que las familias elegidas también cuentan**



# **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, transgender and/or queer/questioning (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

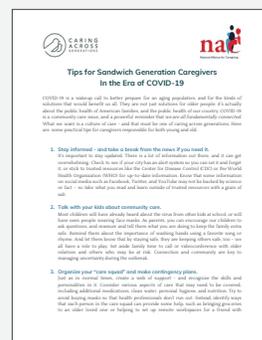
These resources focus on the impact COVID-19 has across Indian Country including tribes, Urban Indian Health Programs, and urban Indian communities.

### 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 vitally, 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

These informational flyers were produced by NHCOA and are available in both English and Spanish.

**Get your updated booster shot! (ENG + SPA)**

**Why should Latinos get their flu shot? (ENG + SPA)**

**Get your COVID-19 vaccine (ENG + SPA)**

**Self-Test at Home or Anywhere (ENG + SPA)**



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

 LinkedIn

 Facebook

 Twitter

