

Caring for Those Who Care

Meeting the needs
of diverse family
caregivers

**Diverse Elders Coalition
2020**



**DIVERSE
ELDERS
COALITION**



Welcome

- ◆ **SPEAKER INTRODUCTION**
- ◆ **ATTENDEES ALL PROVIDE THEIR:**
 - Name
 - Pronouns
 - Organization
 - A challenge or success they've had in working with diverse family caregivers

Learning Objectives

1.

IDENTIFY AND ADDRESS

the unique needs and caregiving realities of family caregivers from communities of color, American Indian and Alaska Native communities, and LGBT communities

2.

GAIN AN UNDERSTANDING

of how culture and language impact family caregiver perceptions and health outcomes

3.

DEVELOP CULTURAL COMPETENCY

and learn organizational, communications, and policy best practice strategies to engage diverse family caregivers

Ground Rules



Confidentiality



One speaker at a time



Use respectful language



Open and supportive discussion



Participation is key

Who Are Diverse Older Adults?

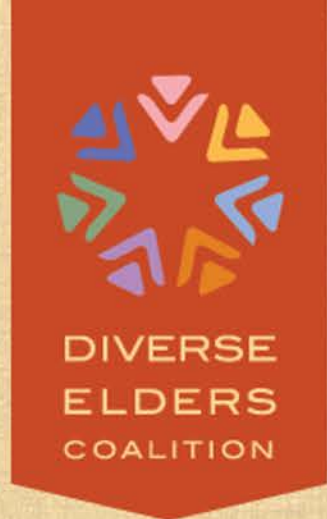
- ◆ African American/Black People
- ◆ American Indian and Alaska Natives (AI/AN)
- ◆ Asian American, Pacific Islanders (AAPI)
- ◆ Southeast Asian Americans (SEAA)
- ◆ Hispanic/Latinx People
- ◆ Lesbian, Gay, Bisexual, and/or Transgender (LGBT) People





DIVERSE ELDERS COALITION

- **FOUNDED IN 2010** to ensure that the unique needs and perspectives of diverse elders would be heard when and where it mattered.
- **SIX ORGANIZATIONS** representing people of color; American Indian and Alaska Native; and lesbian, gay, bisexual and/or transgender (LGBT) people.
- **ADVOCATES FOR POLICIES AND PROGRAMS** that improve aging in our communities.



- **National Asian Pacific Center on Aging (NAPCA)**
www.napca.org
- **National Caucus and Center on Black Aging (NCBA)**
www.ncba-aging.org
- **National Hispanic Council on Aging (NHCOA)**
www.nhcoa.org
- **National Indian Council on Aging (NICOA)**
www.nicoa.org
- **SAGE**
www.sageusa.org
- **Southeast Asia Resource Action Center (SEARAC)**
www.searac.org



DIVERSE
ELDERS
COALITION

Diverse Family Caregiving Challenges

- Lack of culturally competent resources and services
- Lack of research about diverse populations
- Limited financial resources
- Social isolation and loneliness while caregiving
- Need for time and tools for self-care



The John A. Hartford Foundation

Dedicated to Improving the Care of Older Adults

SUPPORT FOR OUR EFFORTS WITH A GRANT TO:

- Analyze existing research
- Generate original research
- Develop policy and programmatic solutions to meet the needs of diverse family caregivers

www.johnahartford.org

Goals of the Caregiving Initiative

1.

IDENTIFY AND ADDRESS

the unique needs of family caregivers for diverse elders.

2.

TRANSFORM THE CAPACITY

and cultural competencies of the healthcare service network to better address those needs, utilizing the voices and experiences of the caregivers and elder care recipients themselves.



**18 STAKEHOLDER
INTERVIEWS**



1100 RESPONDENTS
for Community Caregiving Survey



**36 FOCUS
GROUPS**



93 AFFILIATES ACROSS 25 STATES
invited to participate



**ENGAGEMENT WITH DIVERSE FAMILY
CAREGIVERS** at multiple points throughout
training curriculum development



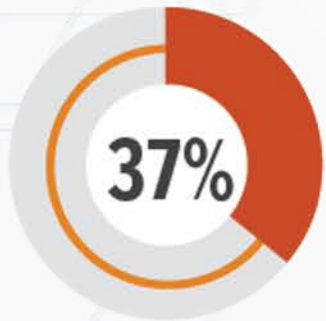
An Aging, Diversifying Nation

WE DEFINE DIVERSE ELDERs as the elders of color, American Indian and Alaska Native elders, and LGBTQ elders living in the United States and its territories.



Currently, one in five elders in the United States is a person of color or American Indian/Alaska Native.

- By 2040, it will be one out of three.



Three out of every eight LGBT adults are elders.

- With the first generation of LGBT people to come out during and after Stonewall growing older and increasing visibility, this number is expected to increase as well.





Common Challenges

- ◆ **ASIAN AMERICAN CAREGIVERS** found to have more limited knowledge of symptoms, treatments, diagnosis of Alzheimer's & Related Dementias
- ◆ **AMERICAN INDIAN/ALASKA NATIVE CAREGIVERS** report distrust of majority culture, hesitant to utilize healthcare services

Common Challenges

◆ **HISPANIC AND AFRICAN AMERICAN CAREGIVERS** reported:

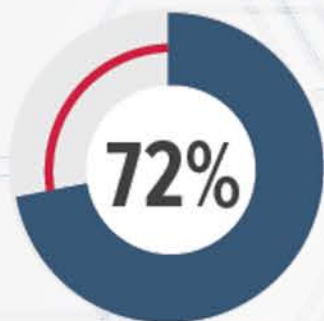
- Ignored and excluded from conversation about care they provide
- Receiving little or no formalized training on homecare tasks
- Confused about medication management
- Discriminated and stereotyped by healthcare professionals

(Reinhard & Choula, 2012)

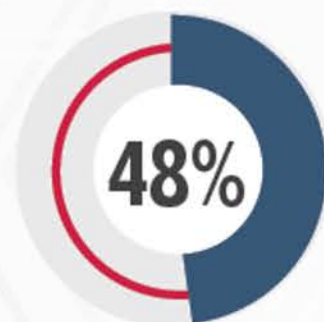
◆ **CAREGIVERS WHO IDENTIFY AS A GENDER AND/OR SEXUAL MINORITY** reported being discriminated by healthcare providers



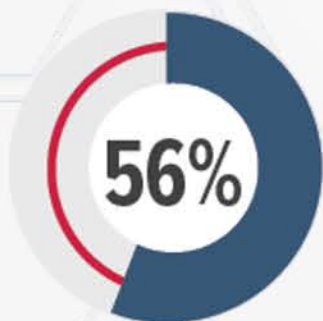
Who were the caregivers who responded to our survey?



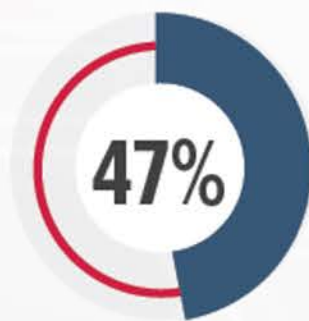
FEMALE



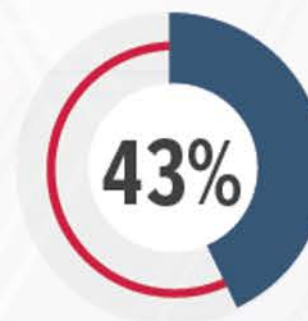
MARRIED



BORN IN
USA



LIVE WITH
CARE
RECEIVER



ONLY PERSON
WHO CAN
PROVIDE CARE

Culture as a Reason for Caregiving

- ◆ **SURVEY RESPONDENTS**, on average, agree that cultural obligation is a reason they provide care for a relative or friend
- ◆ **AMERICAN INDIAN/ALASKA NATIVE CAREGIVERS** reported more cultural commitment to caregiving than Asian, LGBT, and African American/Black caregivers
- ◆ **LGBT CAREGIVERS** reported less cultural commitment to caregiving than African American/Black, Hispanic/Latino, and American Indian/Alaska Natives caregivers



Comparing Caregivers

CAREGIVERS WHO WERE BORN IN THE U.S.

- Younger**
- Higher Incomes**
- Higher Educational Degrees**
- Assisted care receivers with more health-related tasks* but fewer cultural tasks (like translating health information)**
- Reported higher levels of relationship strain*
- Rated their relatives healthcare as being of lower quality*

* $p \geq .05$ ** $p \geq .01$

Comparing Caregivers

CAREGIVERS WHO WERE NOT BORN IN THE U.S.

- More likely to be older
- Lower income
- Lower Educational Degrees
- Assisted care receivers who used less professional services or paid help*
- Less likely to report they provided care because it was more convenient for them to fill this role than other family members or friends**

* $p \geq .05$ ** $p \geq .01$



IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS



54%

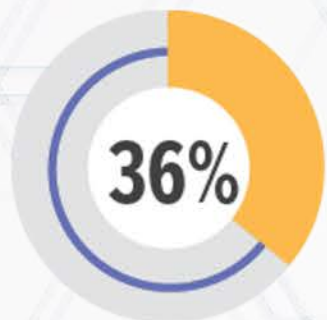
of African American/Black caregivers report some or great deal of difficulty with healthcare tasks such as medication management or caring for wounds



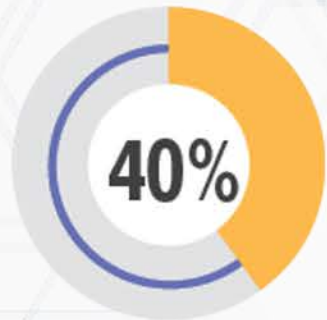
56%

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

IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS



OF AMERICAN INDIAN/ALASKA NATIVE CAREGIVERS report some or great deal of difficulty with healthcare tasks such as medication management or wound care



REPORTED some or great deal of difficulty with coordinating or arranging for care services from doctors, nurse, social workers, etc



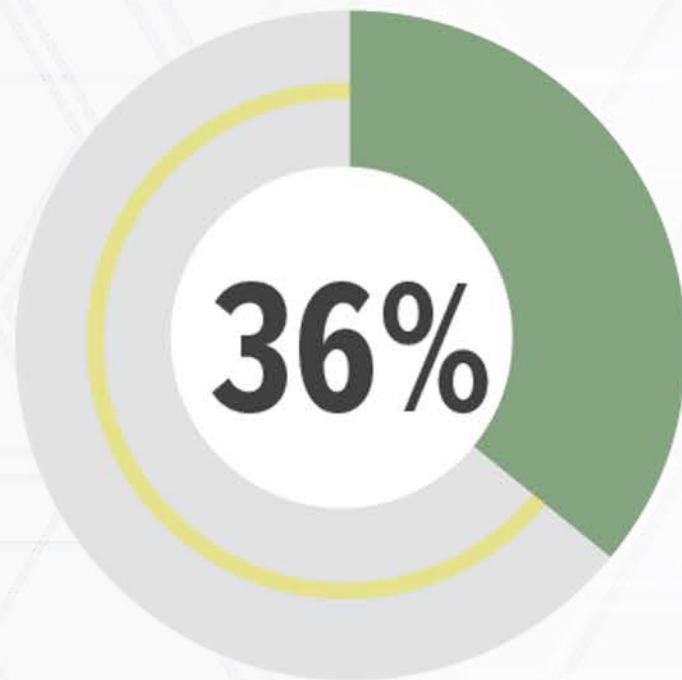
DISAGREED that healthcare providers know about the help they provide to care receivers

IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS

- ◆ On average, Chinese American caregivers agree that cultural obligation is a reason they provide care for their relative or friend
- ◆ 16.3% of Chinese American caregivers reported some or a great deal of difficulty assisting with cultural tasks
 - Overcoming language barriers when talking with healthcare or service providers
 - Translating health-related information into primary language
 - Legal issues related to immigration or naturalization procedures
- ◆ Caregivers who report more difficulties performing cultural tasks have higher levels of four types of caregiver strain** and depression**

** $P < .01$

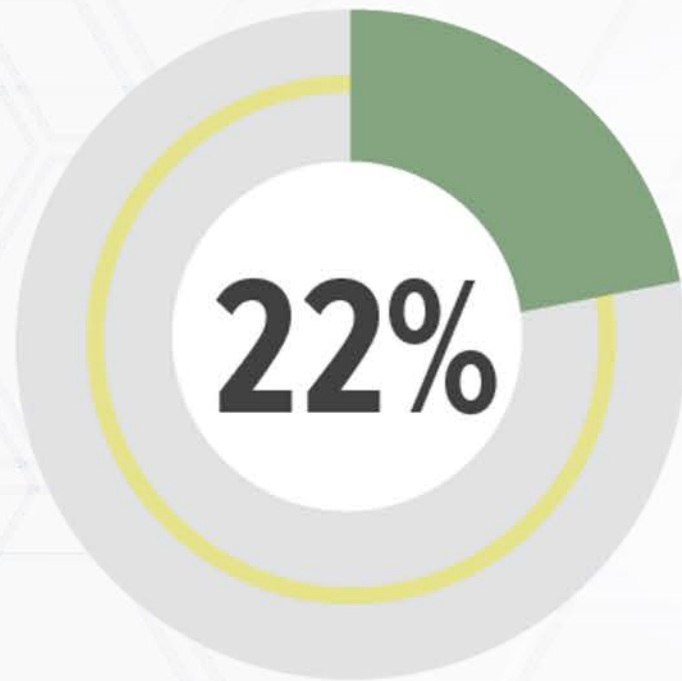
IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS



ONE THIRD OF SEAA CAREGIVERS
reported some or a great deal of difficulty
assisting with cultural tasks, including:

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

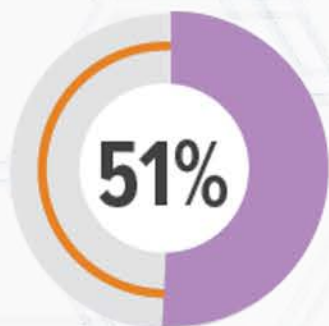
IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS



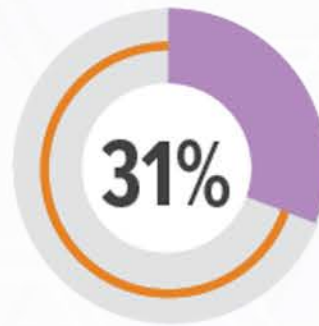
MORE THAN ONE IN FOUR
SEAA caregivers agreed that
caregiving had negative effects
on their physical/emotional
health agreed to feeling isolated
due to caregiving.

IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS

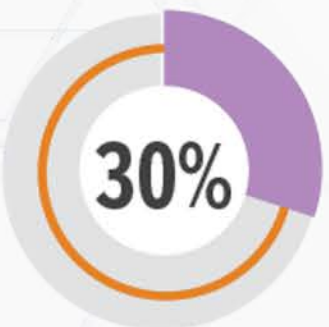
◆ A LACK OF INFORMAL AND FORMAL SUPPORT increases strain for caregivers



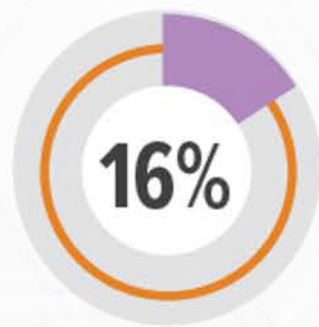
Agree that they are
the only person to help
care recipients



Agree that caregiving had
negative effects on their
physical/emotional health



Report feeling more
isolated due to
caregiving



Report feeling more
symptoms of depression
sometimes or often

IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS



23%

DISAGREED that healthcare providers know about the help they provide to care receivers



63%

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



IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS



37%

MORE THAN A QUARTER of LGBT caregivers agreed 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
- LGBT older adults more likely to be isolated than non-LGBT older adults



19%

REPORTED feeling symptoms of depression sometimes or often in the past 4 weeks

Assistance with Cultural Tasks and Health Outcomes

Caregivers who reported more difficulties performing cultural tasks have higher levels of depression and four types of strain:

- Isolation**
- Health strain**
- Relationship strain**
- Work strain**

** $p < .01$

Cultural tasks include translating health information into languages other than English, interpreting at the doctor's office, and/or navigating the immigration system.



1.

FAMILY CAREGIVERS HAVE VARIED RACIAL AND ETHNIC IDENTITIES, SEXUAL ORIENTATIONS, AND GENDER IDENTITIES. They are providing a range of supports for their loved ones. They may not identify as a “caregiver.”

2.

MANY DIVERSE FAMILY CAREGIVERS HAVE A STRONG CULTURAL COMMITMENT TO CARING, which impacts their own health as well as the health of the people for whom they are caring.

3.

**UNDERSTANDING THE DIFFERENT CULTURES
AND IDENTITIES OF THE CAREGIVERS YOU SERVE**

can have a lasting, positive impact on the quality of care they receive—and the quality of care they provide.

4.

**THERE ARE CONCRETE, PRACTICAL STEPS THAT
PROVIDERS CAN TAKE**

to improve their cultural competency and understanding of the needs of diverse family caregivers.

“Having my parents with me and having the opportunity to take care of them is gratifying and valuable. I do it with great honor.”

Latina caregiver, Silver Spring, MD

Strengths of Diverse Caregivers

Value and actively care for older adults

Fiscally aware and supportive

Accustomed to balancing many priorities

**1/2 of survey participants agree that culture expects them to care
for older relatives or friends**

Best Practices - Organization

- Ongoing cultural competency training for leadership + staff of your organization
- Ensure your organization's nondiscrimination policy includes sexual orientation, gender identity and expression
- Recruit, promote, and support a diverse workforce that understands/represents the culture of the community
- Develop caregiver training inclusive of diverse communities



Best Practices - Provider

- Develop caregiver support programs for diverse communities
- Provide culturally competent referrals and resources that are affordable and in language
- Development of culturally and linguistically competent in-office and multimedia materials
 - 5th grade reading level or lower
 - Avoid words of more than two syllables
 - Pictures to illustrate key content



Best Practices - Provider

- Listen for understanding to caregiver concerns
- Focus on one concept at a time and support caregiver decisions
- Reflect back the words people use to describe their identities and relationships



Best Practices - Policy

- Utilize culturally competent, trained Medical Interpreters when speaking to LEP (Limited English Proficiency) family caregivers
 - LEP patients were 27% more likely to be readmitted
- Assess for difficulty with culture-related tasks in caregiver & patient screening
 - Respondents who reported high difficulty with culture-related tasks had more poor health outcomes than patients who reported low difficulty
 - Caregiver Burden Screening



REFLECTION

Future Learning

WWW.DIVERSEELDERS.ORG/CAREGIVING



Thank You

To our 92 affiliate
organizations

AND TO

The John A. Hartford
Foundation



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