Caring for Those Who Care
Meeting the needs of diverse family caregivers

Diverse Elders Coalition
2020
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
• **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.
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
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
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.
COMMUNITY DRIVEN PROCESS

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

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

(Reinhard & Choula, 2012)
Who were the caregivers who responded to our survey?

- 72% Female
- 48% Married
- 54 Average Age
- 56% Born in USA
- 47% Live with Care Receiver
- 43% 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 ≥ .05  **p ≥ .01
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.
AMERICAN INDIAN AND ALASKA NATIVE CAREGIVERS

IMPACT OF CULTURE ON THE HEALTH OF CAREGIVERS

36% report some or great deal of difficulty with healthcare tasks such as medication management or wound care.

40% reported some or great deal of difficulty with coordinating or arranging for care services from doctors, nurses, social workers, etc.

20% disagreed that healthcare providers know about the help they provide to care receivers.
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**.
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
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.
A LACK OF INFORMAL AND FORMAL SUPPORT increases strain for caregivers

- Agree that they are the only person to help care recipients: 51%
- Report feeling more isolated due to caregiving: 30%
- Agree that caregiving had negative effects on their physical/emotional health: 31%
- Report feeling more symptoms of depression sometimes or often: 16%
Impact of Culture on the Health of Caregivers

- Disagreed: 23% that healthcare providers know about the help they provide to care receivers.
- Reported: 63% some or great deal of difficulty coordinating or arranging for care services from doctors, nurses, social workers, etc.
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

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.
KEY TAKEAWAYS

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

½ 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
Thank You
To our 92 affiliate organizations
AND TO
The John A. Hartford Foundation