Caring for Those Who Care

Meeting the needs of diverse family caregivers

Lauren Pongan Diverse Elders Coalition

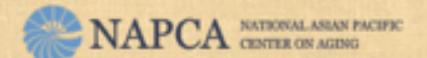




DIVERSE ELDERS COALITION

- 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.















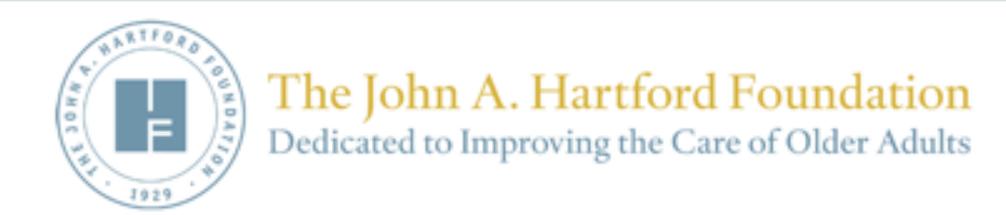
- National Asian Pacific Center on Aging (NAPCA) www.napca.org
- National Caucus and Center on Black Aging (NCBA) www.ncba-aging.org
- National Hispanic Council on Aging (NHCOA) www.nhcoa.org

- National Indian Council on Aging (NICOA) www.nicoa.org
- SAGE www.sageusa.org
- Southeast Asia Resource Action Center (SEARAC)
 www.searac.org



Diverse 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

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.

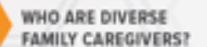
 With the first generation of LGBT people to come out during and after Stonewall growing older and increasing visibility, this number is expected to increase as well.



Who is a caregiver?

PERSONS 18 YEARS OF AGE AND OLDER, who provide ongoing help without pay to a parent, grandparent, relative, spouse, partner, friend, or neighbor who is 55 years of age or older and needs assistance because of ongoing health problems or disabilities.

The person giving help and the relative or friend getting help can live in the same household, or in different households. They can live in the same city, in different parts of the US, or in different countries. Helping someone who is far away could be done by telephone, mail, or email.



The words we use for "caregivers"

"Carer" "Cuidador" "Chosen "Friend" Family"

In many non-English languages, there is no word for "caregiver."

The Diverse Family Caregiving Survey

WHAT DID WE WANT TO LEARN?

- Primary objective and subjective stressors of caregiving
- Secondary stressors and well-being outcomes for caregivers
- Support resources for caregivers and care receivers



DIVERSE FAMILY CAREGIVING SURVEY

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55 세 이상인 전혀, 참안다. 민안나 이용을 한 번 이상 등고 계약하면 그 한 번 병을 생리하시기 그 작업인 점투에 두고

네 점은 교사에 설문에 대한 남은 당한 것도 들면 것도 없습니다. 기계는 다시 중앙에서는 본에 경쟁을 다른데 建设计 宗备 医食心化 对 医外轮 称瞳形状态,腹腔形成 医锁骨 的复数 的现在分词形式 计特别的 医髓管 对照规律 생산에 무소합니다. 여러운의 순압은 전혀지나 있으면 했고 있는 다른 400 세계의 중심에 함께될 것입니다. 이 설립이는 공연에 마지는데 20~30 분이 설립하다. 마리이면 여러운이 들어진 시간에 대한 보답이 되어도 20 살이 學學問 对原则 特瓦爾 巴黎山區

이 설한 교사는 속에도 사례적인 인다면 및 함께스러 원주면, 그리고 배드에면, 계시, 당한에게, 상점원이 한 성적 소수가 여러시킨에서 느낀 생활 가장을 위해 받아는 없는 것은 안된 생조님 이렇게 살이 음료산에 생활한 소수 느낌 문화(Server-Ellier Challian)의 설식적인 경찰식은 소화에도 한 환역활동으로 있는 역명된 음식 및 성공 THE WAY BE MY STAY Brighten Store Statistics to Aging \$1. If \$1.00 \$14 AT MY STEP 重要用品 蓝蓝山杉,同 服务 工作的 上型 及集 准备者 经自购款 表情明有 作業 用食物制剂 表点 经汇集区 #Wille John A. Alextery Franchiscom Schille 1984 Warrier.







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Caregiving Focus Groups

8 LANGUAGES

15 CITIES

- In-language focus groups (eight different languages)
 for each of the DEC constituencies
- Able to have in depth conversations, learn the community stories to provide additional insights not generally addressed in quantitative research

SURVEY TRENDS



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

SURVEY TRENDS

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



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

SURVEY TRENDS

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**

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."



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.



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.



THERE ARE CONCRETE, PRACTICAL STEPS THAT PROVIDERS CAN TAKE to improve their cultural competency and understanding of the needs of diverse family caregivers.

BEST PRACTICES

General Best Practices Amid COVID-19 Crisis

- Promote telehealth/telemedicine services to provide health-related services and information
 - Mental health support
 - Provide COVID-19 related information
 - Include "LGBT-friendly" in promotion



General Best Practices Amid COVID-19 Crisis

- Transition to online/telephone/virtual programs to provide for diverse caregivers
 - Online/telephone/virtual support groups
 - Volunteer-based connection programs to provide caregiver respite
 - In-language helplines to provide trusted information and resources
- Establish partnerships with trusted community-based organizations and/or community leaders to reach diverse caregivers



Action Planning



How can you incorporate these into your practice?



What additional resources do you need to do so?



What barriers to change will you encounter?

Thank You

To our 92 affiliate organizations

AND TO

The John A. Hartford Foundation





www.diverseelders.org/caregiving

Twitter/Facebook: @DiverseElders

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