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

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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 Family”  “Friend”

* 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
ENCUESTA PARA PERSONAS QUE CUIDAN CIFRADORES DE ALGUN FAMILIAR O AMIGO MAYOR DE 55 AÑOS

Esta encuesta es dirigida para adultos (mujeres de 18 años) que brindan ayuda sin compensación a un familiar, amigo o vecino mayor de 55 años y descubren algunas entidades debido a problemas relacionados con el cuidado. El objetivo de esta encuesta es entender las opiniones y experiencias de los cuidadores de adultos mayores de 55 años en varios problemas de salud y discapacidad. Se discute de mejorar las vias de salud tanto para el cuidador como para el adulto mayor.

a) Encuesta de la persona que cuida en cuidados de su familia o amigo mayor de 55 años.

b) Encuesta de la persona que cuida en cuidados de su familia o amigo mayor de 55 años.

III) CUIDADORES DE ADULTOS MAYORES: ACTIVIDADES DIARIAS Y DE SALUD

Cuando se trata de cuidar a un adulto mayor, es importante entender las necesidades de salud y discapacidad. En esta sección, se discuten algunos de los posibles problemas de salud que pueden surgir en adultos mayores, incluyendo la pérdida de habilidades, problemas de salud mental y física, y cambios en el estilo de vida. Se sugiere la necesidad de una mejor asistencia en cuidados de salud y discapacidad, tanto para el cuidador como para el adulto mayor.

IV) CONCLUSIONES

En resumen, esta encuesta busca mejorar la comprensión de las necesidades de cuidado de adultos mayores y discutir la importancia de una mejor asistencia en cuidados de salud y discapacidad. Se sugiere que la encuesta sea utilizada para mejorar la comprensión de las necesidades de salud y discapacidad de los adultos mayores, tanto para el cuidador como para el adulto mayor.
Caregiving Focus Groups

- 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
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)
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.
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.
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