

**Family Caregiving Advisory
Council Meeting
April 28, 2021**



Opening Remarks

Alison Barkoff

Acting Administrator and Assistant Secretary for Aging
Administration for Community Living



Roll Call

Agenda Overview and Updates

Greg Link, Director
Office of Supportive and Caregiver Services
Administration for Community Living



Agenda

1:30 – 2:30 Older Adults Equity Collaborative (OEAC) Presentation

2:30 – 3:15 Listening Sessions Presentation

3:15 – 3:30 Break

3:30 – 4:15 Initial Report to Congress – Final Review & Discussion

4:15 – 4:30 Wrap-up and next steps



Older Adults' Equity Collaborative





Who are we?

- MHP Salud is a national non-profit organization that has served the Latino community for over 35 years through Community Health Worker (CHW) programs. We promote the CHW profession nationally as a culturally appropriate strategy to improve health.
- MHP Salud implements CHW programs, including programs serving Latino older adults, and provides training and technical assistance nationally to organizations seeking to improve their services.

The American Public Health Association has adopted the following definition of **Community Health Worker**

A Community Health Worker is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.

A Community Health Worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.

In other words...

A Community Health Worker is a trusted member of the community who empowers their peers through education and connections to health and social resources.



Characteristics of Hispanic/Latino older adults and families

- **Diverse Group**
 - Various countries of origin
 - Language: 73% of Hispanics in the US speak Spanish at home (PEW Research, 2017)
- **Growing Older Adult Population**
 - 1 in 5 older adults will be Hispanic by 2060 (ACL,2018)
 - 1 in 4 Hispanic non-caregivers expect to become a caregiver within the next two years (CDC, 2017)
 - 38% of Hispanic family caregivers are between 18 and 34 (AARP, 2018)



Characteristics of Hispanic/Latino older adults and families Continued

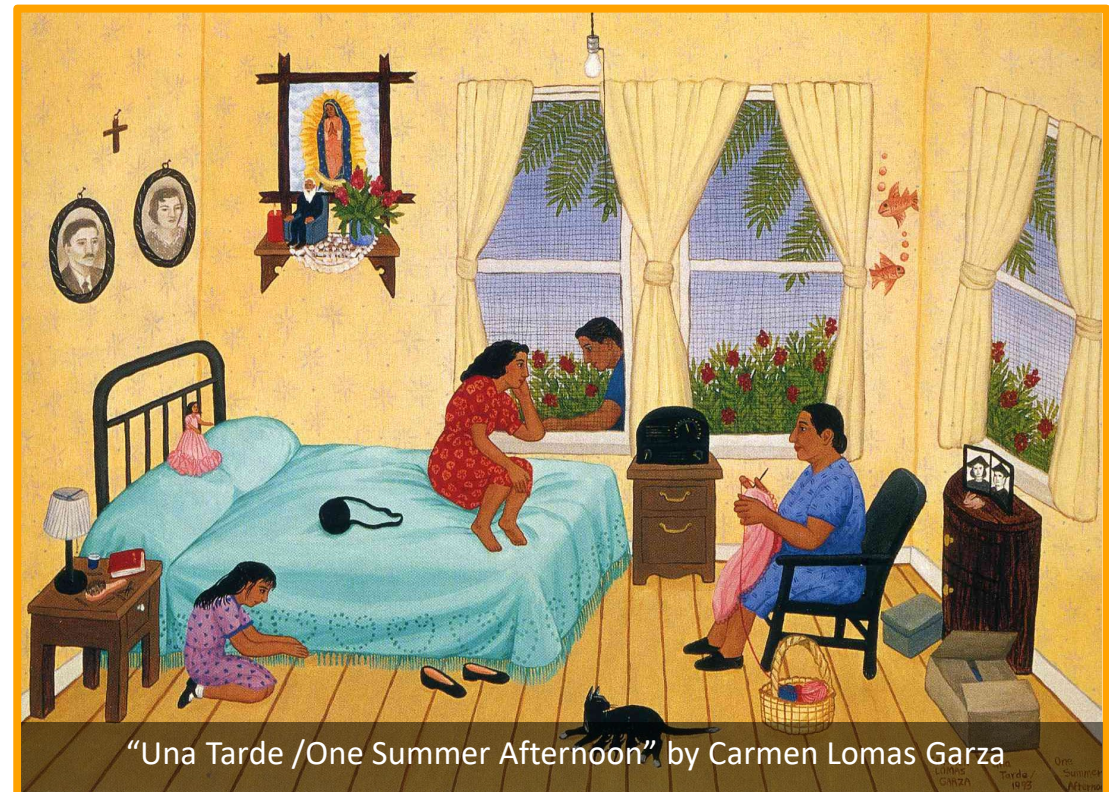
- **Immigration**
 - Acculturation (1st, 2nd, 3rd generations or more)
 - Mixed status families and fear of using eligible benefits
 - Immigration-related trauma
- **Medical Mistrust**
- **Cultural and Religious Beliefs**
 - Influence caregiving and medical decision making
 - 69% of the Latin American population is Catholic (PEW Research, 2014)
 - *Familismo*



Familismo

Familismo or familism is the cultural value/concept of putting family above the self.

- Preference for family caregiving (caregivers living within the household)
- Sense of purpose to take care of older adult, respect for older adult
- Family caregivers less likely to prioritize/practice self-care and seek support



“Una Tarde /One Summer Afternoon” by Carmen Lomas Garza

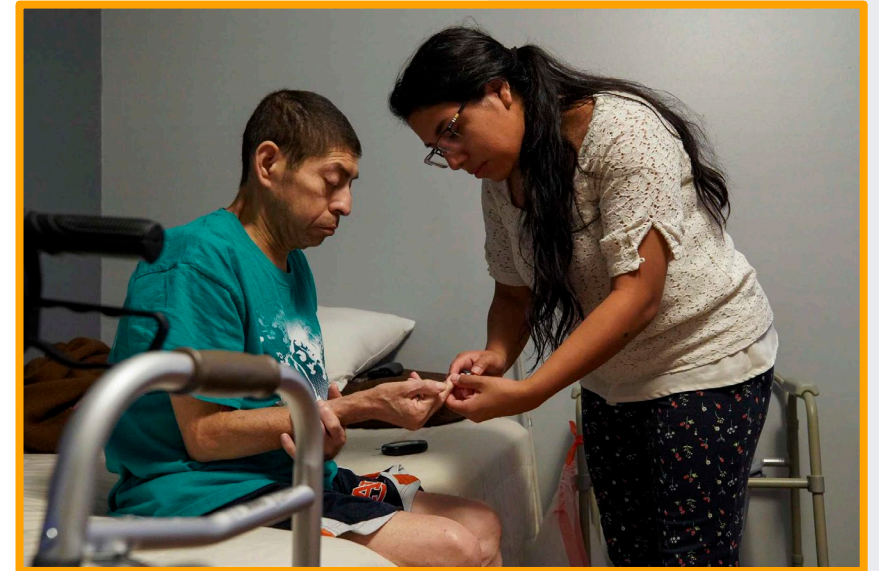
Unique Challenges for Family Caregivers

1. Cultural influences

- Preference for family caregiving
- **Multigenerational** homes
- More likely to **live with care recipient**
- Family should be included in **decision-making** processes
- 50.9% of Hispanic caregivers agree that they are the only person to help their care recipient (NHCOA, 2017)

2. **High-intensity/Higher burden** caregiving situations (AARP, 2020)

- The Hispanic/Latino older adult population more likely to have **more than one chronic condition**.
- Hispanic caregivers more likely to help with **nursing/medical tasks** than white caregivers (AARP, 2020)
- Disproportionate rates of dementia, anxiety and depression than white older adults.
- 45% experience **higher burdens and more time a week** (32 hours) on average taking care of impaired family member vs 33 % and 20 hours for whites (AARP, 2020)



Unique Challenges for Family Caregivers Continued

3. **Negative health effects** for caregivers (NHCOA, 2017):

- Risk factors for caregiver negative health effects: level of impairment of person caretaking for, living with care recipient, lack of choice in taking-on caregiving role, low SES, among others.
- 30.3% reported agreeing to feeling more socially isolated due to caregiving
- Hispanic caregivers reported higher rates of social isolation, negative effects on their physical/emotional health, depression (DEC, 2020)

4. Hispanic caregivers most often report having **no source for help or information**. (AARP, 2020)

- Do not self-identify as caregivers
- Not aware of supports and services; do not know where to turn to for guidance, relief, and support for caregiving activities (NCHOA, 2017)

5. **Financial strain**

- Lower wage, hourly jobs, limited benefits
- High burden, long-hours dedicated to caregiving can affect long-term career advancement

6. **Lack of culturally appropriate materials and medical staff**

- Caregivers are often required to translate and not included in decision-making



Ideas for Addressing Unique Challenges for Family Caregivers

I. Awareness and Outreach

- Outreach efforts (public service announcements, partner with local and trusted health centers, community-based organizations and religious institutions, CHW programming)

II. Need for culturally and linguistically appropriate care

- Promote diversity among medical professions
- Training for service providers
- Accountability

III. Services and Supports (higher caregiver burden)

- Increase caregiver screenings (NHCOA, 2017)
- Outreach efforts to educate about available supports (public service announcements, partner with local and trusted health centers, community-based organizations and religious institutions, CHW programming)

IV. Address financial barriers

- Paid family leave / extension to lower wage hourly positions

Funding for Community Health Workers

- **Medicare** reimbursement for CHW services
- **Grants** for CHW programs serving family caregivers
- Consider insurance reimbursement options for CHWs (care-facilities, other types or orgs can bill insurance companies)





NATIONAL ASIAN PACIFIC
CENTER ON AGING

Asian American & Pacific Islander Caregivers – RAISE ACT
Recommendations

Joon Bang, President & CEO



NAPCA envisions a society in which all Asian Americans and Pacific Islanders (AAPIs) age with dignity and well-being.

In-language and culturally competent (cultural humility) resources

- National Community Resource Helpline for Older Adults and Caregivers

Minority Organization Technical Assistance Resource Center (TARC) w/ Administration for Community Living (ACL)

- 1 of 5 minority organizations in the US providing targeted technical assistance and training to the aging services network and other relevant stakeholders and consumers

Advocating for the unique needs of AAPI family caregivers and diverse AAPI representation in research

- CARE Project (www.careregistry.ucsf.edu)
- COMPASS Project (www.compass.ucsf.edu)

Supporting a mature workforce and building economic security

- Senior Community Service Employment Program (SCSEP) w/ Department of Labor (DOL)
- Senior Environmental Employment Program (SEE) w/ Environmental Protection Agency (EPA)



Los Angeles Times



OPINION



Opinion: Koreatown needs a homeless shelter. It also needs city officials to learn from the mistakes of the past

By JOON BANG

MAY 18, 2018 4:05 AM PT

“Dowajuseyo.” In Korean, it means “help me.”

A few months ago, I received a call from an L.A. County mental health facility. They had just taken a frail Korean grandmother into their care, and officials couldn’t figure out what to do with her. In her 70s, with a full head of gray hair, the woman probably weighed no more than 85 pounds and had been living on the streets after being evicted from her Koreatown home. She was afraid to be alone in a facility with people who were unable to communicate with her and wanted to be released.

I often find myself in this somewhat fraught position — a bridge between the limited-English-speaking Korean immigrant community and the service providers who have the resources to help them. I spoke with the grandmother’s family, who told me that their financial hardship made their grandmother’s mental illness difficult to manage on their own. I tried again and again to broker some kind of arrangement. Ultimately, we were unable to find a solution. The grandmother was released to the streets. She’s currently among a growing number of Korean American seniors who are experiencing homelessness.

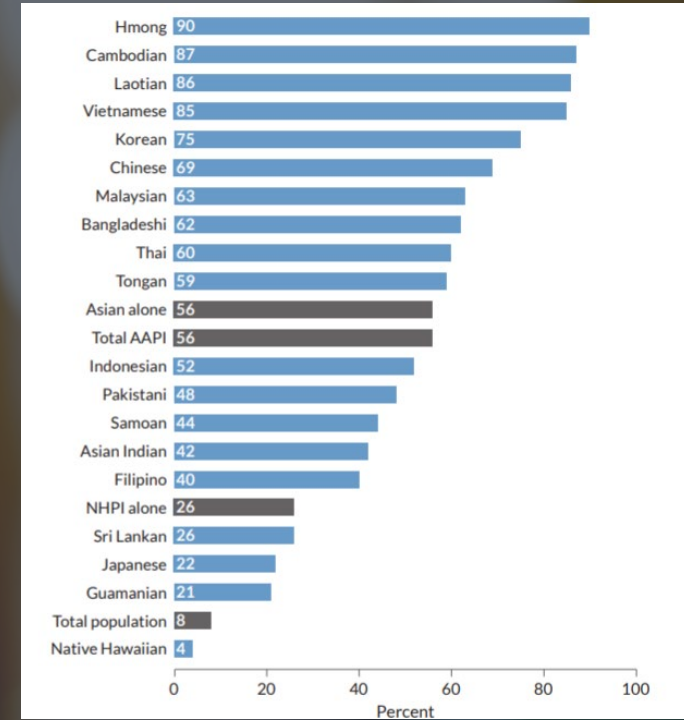




The Importance of acknowledging diversity in Asian American Pacific Islander communities

- AAPIs are a heterogeneous group representing more than 50+ unique cultural and racial identities originating from the Asian continent or the Pacific islands.
- Asian Americans are the fastest growing racial group in the US
 - 7% of the population
 - 20 million Asian Americans
 - 1.6 million Pacific Islanders
- AAPIs 55+
 - 4%+ of the total US older adult population
 - 20%+ of the total AAPI population
- AAPIs represent over 100 spoken languages
- 56%+ of Asian older adults are Limited English Proficient (LEP)
 - “Speaks English less than “very well””
- Language barriers can lead to isolation, loss opportunities, prevent someone from medical and social services
 - Direct impact to quality of one’s life

Source: U.S. Census Bureau, 2009-2011 ACS, 3-Year Estimates





The Importance of Cultural Awareness

- **Cultural awareness** is the first and foundational element of cultural competence. Cultural awareness is defined as being cognizant, observant, and conscious of similarities and differences among cultural groups, and understanding that one's culture may influence values, beliefs, judgments, and decisions (National Center for Cultural Competence, 2016).
- Historically, AAPI cultures are highly group-oriented and place a strong emphasis on the family as the sole source of identity. An example is the Native Hawaiian term, "Hanai."
- The importance of **filial piety** in Asian American Pacific Islander Communities
- **Caveat:** We need to be careful not to generalize, profile, or stereotype people; an individual may, and more likely will, deviate from cultural norms. Each AAPI subpopulation differs in socio-cultural/economic traits and in a variety of other ways. The degree to which a person adopts US cultural values varies, and there may be numerous factors as to why a person may not assimilate as fast, or at all. Poorly understood differences lead to adverse outcomes that result in (1) lower participation rates, (2) delayed action during a crisis, (3) inaccurate history of documentation of an incident, (4) non-compliance with recommendations that an agency provides, and (5) decreased satisfaction of the program or agency (Yale Journal of Medicine and Law, 2006).





AAPI Caregivers

- AAPIs more than any group, believe that caring for parents is expected of them (73% compared to 49% of the general population)
- AAPI families are less likely to put their older family members into a facility in comparison to the general population
- 42% of AAPIs are caring for an older adult vs 22% of the general population
- 17% of AAPIs live in multigenerational households, compared to 7% of the total population
- Despite high rates of caregiving, in 2014, 3% of caregivers served by the Older American's Act were AAPI; 53% were White





RAISE Act Recommendations

Recommendations

- Require collection of disaggregated data for all federally funded caregiver programs
- Require cultural competency training for all federally funded caregiver programs
- Require culturally and linguistically competent and appropriate materials
- Prioritize affordable and in-language referrals
- Establish in-language caregiver support groups and networks on federal level
- Provide as a national resource in-language caregiver education/ training workshops
- Utilize culturally competent, trained Medical Interpreters when speaking to AAPI family caregivers
- Edit caregiver burden screening tools to collect information about caregiving responsibilities



RAISE Family Caregiving Advisory Council

April 2021

National Indian Council On Aging

Rebecca Owl Morgan

Eastern Band of Cherokee Indians

Project Coordinator



National Indian Council on Aging

Mission: to advocate for improved comprehensive health, social services, and economic wellbeing for American Indian and Alaska Native Elders.

- Membership
- National nonprofit established over 40 years ago
- Job training program: SCSEP
- Older Adults Equity Collaborative (OAEC)
- DEC Caregiving Grant
- Long Term Services and Supports (LTSS) Project
- Conference every 2 years. Register now! August 1-6, 2021, in Reno, Nevada

American Indian/ Alaska Native Caregivers are Unique

- 574 federally recognized tribes and 60 state recognized tribes in the United States
- Tribal self governance means that tribes can decide for themselves how to implement and participate in programs for elders and caregivers, tribal approval is necessary
- Rural tribal communities are geographically isolated from care services and resources
- For urban AI/ANs, living far from home can be isolating
- Caregivers can be reluctant to use formal caregiving services
- Caregiving is seen as part of family life



Who can Improve Services and Supports for Caregivers?

- Tribal Leaders
- Tribal Councils
- Elders' Councils
- Tribal Health Departments
- Tribal Clinics
- Indian Health Service (IHS)
- Title VI Directors
- Community Health Representatives (CHRs)
- National Association of Area Agencies on Aging (n4a)
- Area Agencies on Aging (AAA)



NICOA's Recommendations to the Family Caregiving Advisory Council (FCAC)

Awareness and Outreach

- Caregivers may not identify as caregivers
- Raise the community's awareness with educational events, broad national media campaigns, video stories focused on AI/AN caregivers, public service announcements
- Creative approaches will be needed in delivering messages because some caregivers may not be reachable via the internet

Partners in Healthcare

- Train healthcare workers, IHS, CHRs, Veterans Administration to provide educational resources to caregivers when they accompany patient to appointments
- Train CHRs to focus a portion of their home visits on the needs of the caregiver



NICOA's Recommendations to the Family Caregiving Advisory Council (FCAC) continued

Services and Supports for Caregivers

- Create support groups
- Devise action steps to improve respite, including how to manage if the person being cared for doesn't want others to help them. Modesty and a sense of privacy being invaded can make the person resistant to change. Tribal clearance process for background checks may slow approval process and delay availability of respite
- Increase access to pharmacies with longer, varying hours
- Education and training for caregivers in managing medical care at home, handling the dynamics of caregiving especially if the person has ADRD, managing challenging family relationships, practicing good self care to protect their health and wellbeing, navigating the healthcare system, and how to participate in care coordination.



NICOA's Recommendations to the Family Caregiving Advisory Council (FCAC) continued

Financial and Workplace Security

- Develop more compassionate policies in workplaces
- Allow flexible time schedules
- Find qualified free or low-cost help locally for financial issues, bill paying, money management (see CFPB's Managing someone else's money guides)
- Find qualified free or low-cost help for issues related to power of attorney, guardianship, wills, and other legal matters

Research data and evidence informed practices

- Begin to track the number of family caregivers in Indian Country
- Regularly screen caregivers for depression



Thank You!

Becky/Rebecca Owl Morgan

Project Coordinator

rmorgan@nicoa.org

505-292-2001

www.nicoa.org

**Keisha Lewis, OTR/L, MS,
CDCES, CAPS**
Consultant, Health and Wellness Program



Who is NCBA?



National Caucus for Black Aging

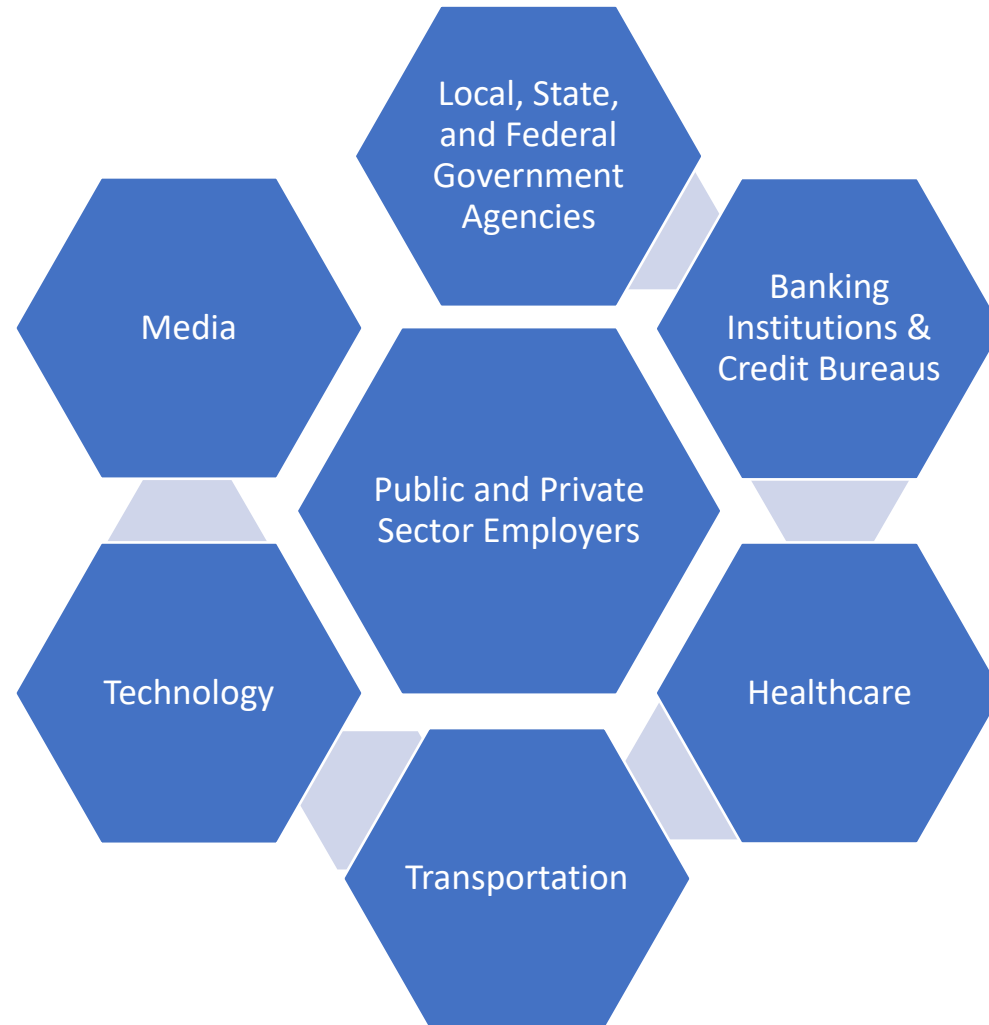
- Oldest minority aging organization in the country.
- Founded in 1970 by nursing home and aging professionals to address the social and economic challenges of African American and Black older adults, their families, and their caregivers.
- NCBA cornerstone programs include health and wellness programming, gerontological research, safe and affordable housing, job training and employment opportunities.
- Since its inception, NCBA provides leadership, guidance, expertise, technical assistance, resources, innovative programming, best practices to policymakers, legislators, nonprofit organizations, academia, government, and business.

What Do We Know About African American and Black Caregivers?

1. Caregiving in the African American and Black community is informed by cultural traditions, expectations, and norms
2. On average, African American and Black caregivers are 47.7 years old.
3. African American and Black caregivers are more likely to be women, younger, and “sandwiched” between caring for more than one person.
4. In 2020, 2.3 million African American and Black men were the primary caretakers for a family member.
5. Caregiving is especially prevalent within the mother-daughter dyad.
6. Daughters are more often unmarried, administer caregiving in their homes, are more likely to provide care for someone who has a long-term or chronic physical condition.
7. Regardless of gender, most African American and Black caregivers— work while caregiving. Most African American and Black caregivers report at least one impact on their work due to their caregiving role (typically going in late, leaving early, or taking time off to provide care).
8. African American and Black caregivers report experiencing financial impacts as a result of providing care—most commonly stopping saving, leaving bills unpaid or paying them late, or taking on more debt.
9. Women caregivers as a whole-- are 2x more likely than non-caregivers to end up in poverty.



Primary Actors Needed to Craft & Carry Out Actions and Strategies



Considerations for the RAISE Family Caregiving Council

Employers

- Encourage and give guidance to employers when it comes to expanding their definition of “family” to include friends, neighbors, and others outside of the traditional family structure.
- Encourage and give guidance to employers when it comes to implementing caregiver friendly workplaces—this includes flex time and telework options, paid family and medical leave, and paid respite.
- Recommend employers to offer Dependent Care Assistance Plans that allow employees to set aside money from each paycheck before taxes to pay for elder care expenses.
- Recommend employers to offer dependent care flexible spending accounts that allow employees to set aside up to \$5,000 tax-free to use for their family's care-related needs.

Banks and Financial Institutions

- Partner with banks and financial institutions to offer caregivers financial planning, retirement readiness, health and long-term care planning, and emergency savings funds tools and resources that promote and lead to economic inclusion.
- Partner with banks and financial institutions to educate caregivers who may be “unbanked”; underbanked, or who lack access to a traditional deposit bank account about the importance of having a banking relationship with an institution that is safe, secure, and offers affordable banking services.
- Partner with policymakers to strengthen consumer protections against the predatory lending practices of payday loan institutions as well as the fees associated with cash-advance shops and check cashing stores--places where African American and Black caregivers tend to also pay their public utility bills, cell phone bills, buy lottery tickets and phone cards – all in one stop.
- Collaborate with Equifax, Experian, and Transunion—the three major credit agencies to ensure fiduciary caregivers have access and understand how to use credit protection tools available to the care recipient and themselves.
- Collaborate with the Internal Revenue Service to raise awareness about the tax credits available to caregivers.

Considerations to the RAISE Family Caregiving Council (Cont'd)

Government (Local, State, and Federal)

- Make recommendations to local, state, and federal government agencies about the importance of developing and disseminating culturally appropriate collateral materials with images and language (e.g., podcast) that reflect African American and Black older adults, their caregivers, and families. **Note:** Most African immigrants identify with their respective ethnicity of origin.

Media

- Collaborate with urban-oriented, multi-media television and radio companies such as BET or Radio One to reach and inform African American and Black caregivers and care recipients about the local, state, and federal supportive services and resources available to them.

Technology

- Address and bring closure to all sides of the digital divide—telehealth and telemedicine are here to stay.
- Collaborate with community leaders, business leaders, policy makers, as well as mainstream and urban media to develop and inform caregivers about the Emergency Broadband Benefit program—a program that provides discounts on broadband service per eligible households and tribal lands.

Transportation

- Collaborate with the National Aging and Disability Transportation Center and the Eldercare Locator, a public service of the U.S. Administration on Aging to ensure urban and rural dwelling caregivers and care recipients are aware and know to use the public transit, paratransit, demand response, taxis, ride sharing, non-emergency medical transportation, and non-profit and faith-based transportation services available to them.

References

Slide 1 - What Do We Know About African American and Black Caregivers?

1. “Caregiving and its Impact on Women” - <https://komentoolkits.org/wp-content/uploads/2015/03/Applying-Culturally-Responsive-Communication-in-Black-and-African-American-Communities-B-AA-Comm.pdf>
2. “Fact Sheet The “Typical” African American Caregiver” - https://www.caregiving.org/wpcontent/uploads/2020/05/AARP1316_CGProfile_AfricanAmerican_May7v8.pdf
3. “What Providers Should Know About African American and Black Family Caregivers” - [https://www.diverseelders.org/wp-content/uploads/2020/10/What-Providers-Should-Know-About-African-American-Family-Caregivers-May-2020.pdf /](https://www.diverseelders.org/wp-content/uploads/2020/10/What-Providers-Should-Know-About-African-American-Family-Caregivers-May-2020.pdf/)

“AOA Information for African American Elders” - https://blackdoctor.org/aoa-information-for-african-american-elders_trashed/
4. “Hidden Truth: 2.3 Million Black Men Are Family Caregivers” - <https://www.nextavenue.org/2-3-million-black-men-are-family-caregivers/>
5. “Why History Matters For African American Female Caregivers” - <https://www.multiculturalcaregiving.net/why-history-matters-for-african-american-female-caregivers/>

“Sons vs. Daughters: The Role of Gender in Caring for Aging Parents” - <https://www.agingcare.com/articles/daughters-care-more-for-parents-than-sons-171474.htm>

“Comparisons of African American and White Women in the Parent Care Role” - <https://academic.oup.com/gerontologist/article/40/6/718/604746>
6. “Fact Sheet The “Typical” African American Caregiver” - https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_AfricanAmerican_May7v8.pdf

“Community and Culture Help Black Caregivers Cope With the Challenges of Family Caregiving” - <https://www.aarp.org/caregiving/basics/info-2021/african-american-caregivers-cope-better.html>
7. “Fact Sheet The “Typical” African American Caregiver” - https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_AfricanAmerican_May7v8.pdf
8. “Fact Sheet The “Typical” African American Caregiver” - https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_AfricanAmerican_May7v8.pdf
9. “Caregiving and its Impact on Women” - https://www.canr.msu.edu/news/caregiving_and_its_impact_on_women

THANK YOU!

sage[®] | Advocacy &
Services for
LGBT Elders

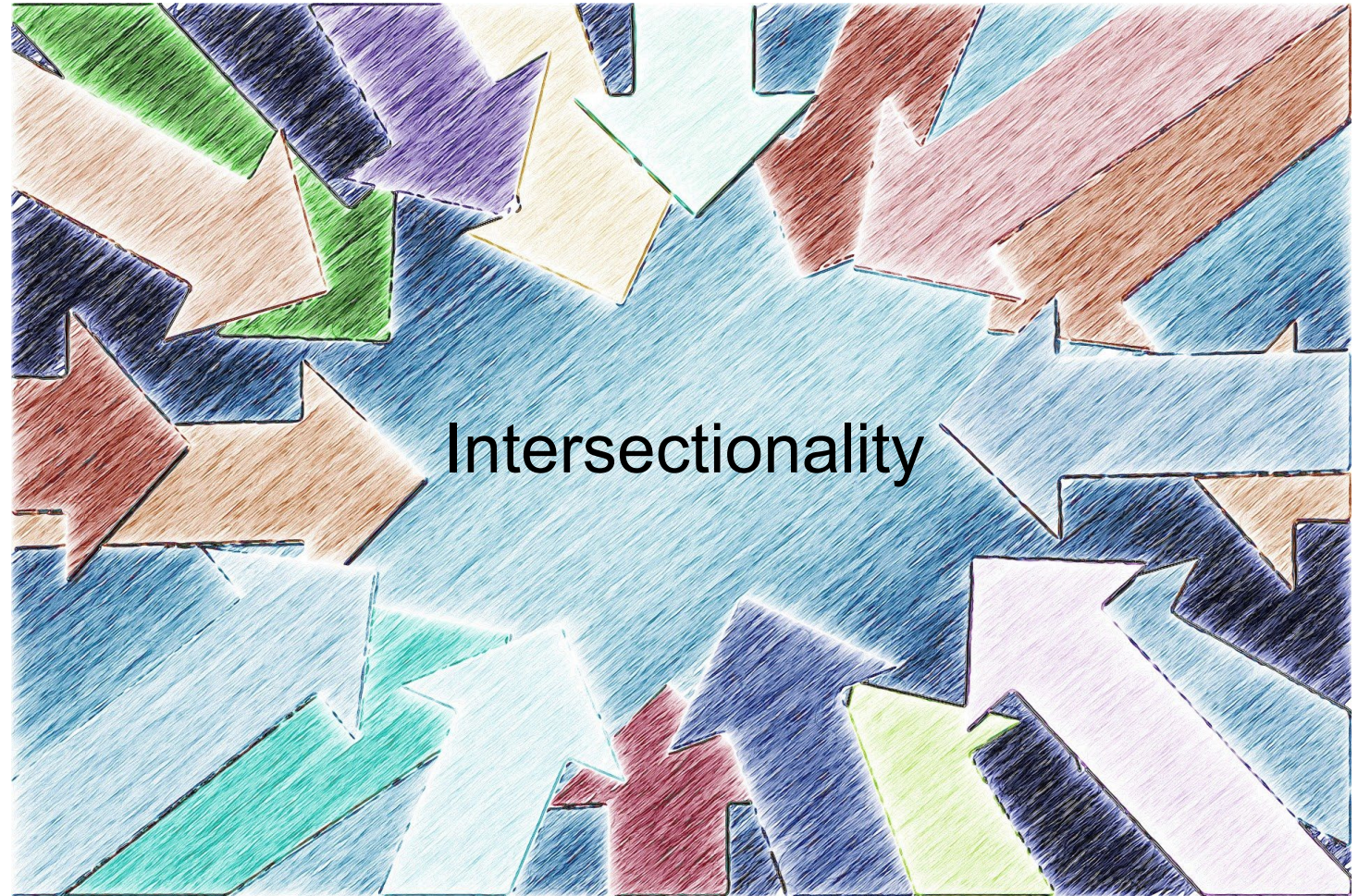
**National Resource Center
on LGBT Aging**

Sherrill Wayland, MSW
Director National Education Initiatives
swayland@sageusa.org

www.sageusa.org
www.lgbtagingcenter.org

SAGE leads in addressing issues related to lesbian, gay, bisexual and transgender (LGBT) aging. In partnership with its constituents and allies, SAGE works to achieve a high quality of life for LGBT older people, supports and advocates for their rights, fosters a greater understanding of aging in all communities, and promotes positive images of LGBT life in later years.

- Ability
- Age
- Class
- Ethnicity
- Gender/Gender Identity
- Race
- Sexual Orientation



Family Caregiving in LGBT Community

Older LGBT People are:

- 2 time more likely to be single and live alone
- 4 times less likely to have children
- Increased risk of poverty
- Increased risk of health disparities



Family Caregiving in LGBT Community

What is known about LGBT Caregiving

- 21% of older LGBT people provide care and support
- 9% of all caregivers identify as LGBT
- Often care in isolation – increasing Stress and burnout
- 54% of older LGBT people receive care support from partner and 24% from a friend



Raise Act Recommendations

Person Centered Supports	Workplace Security	Research/Evidence Based Practices
Require LGBT Cultural Competency Training of all federally funded caregiving programs.	Promote workplace security by including family caregivers with significant relationships in polices such as FMLA.	Require all federally funded research to be inclusive of sexual orientation and gender identity.

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Advocacy &
Services for
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NEW YORK
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OLDER ADULTS' EQUITY COLLABORATIVE COORDINATING CENTER

Crosscutting Themes for Caregivers

Elana Kieffer, MBA



VISION

Everyone has the opportunity to live a healthy life

MISSION

Drive progress towards improved health through attaining health equity

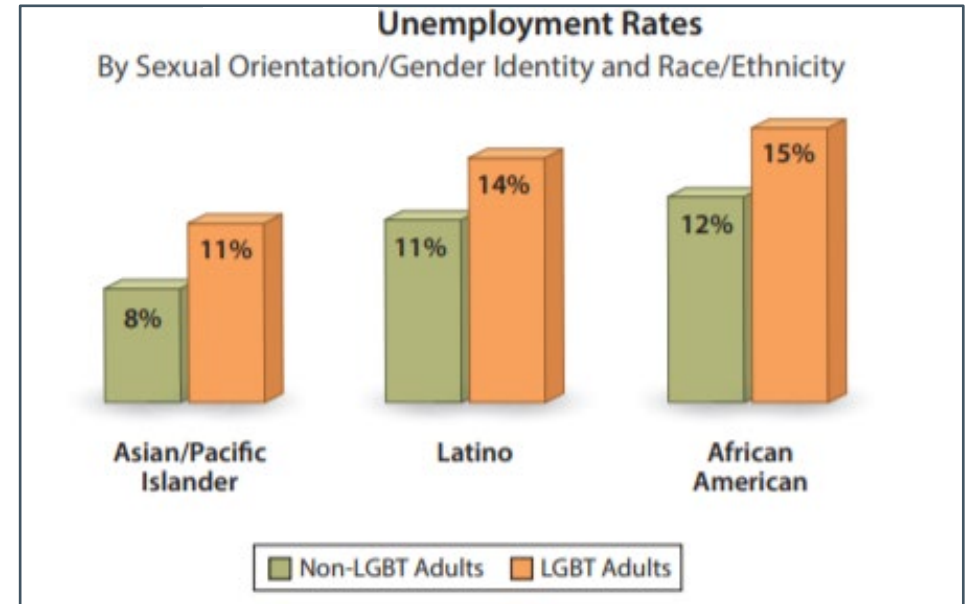
CROSSCUTTING THEMES FOR CAREGIVERS

- Intersectionality
- Cultural expectations
- Language barriers
- Nontraditional family structures
- Financial burden
- Additional themes



INTERSECTIONALITY

The gender wage gap is more significant for most women of color
 Comparing 2018 median earnings of full-time, year-round workers by race/ethnicity and sex



<https://www.americanprogress.org/issues/women/reports/2020/03/24/482141/quick-facts-gender-wage-gap/>

<https://www.lgbtmap.org/file/a-broken-bargain-for-lgbt-workers-of-color.pdf>

CULTURAL EXPECTATIONS

“For [Asian American, Hispanic American, and African American focus group participants], caregiving was an expected part of life that was passed down from generation to generation. In fact, **caregiving was so embedded in the life experience** for some of the groups that the decision to care or not to care was irrelevant; **caregiving was just something that was done without question**. To provide care for one’s family or community was deeply rooted in the cultural subconsciousness, arising “naturally” without conscious thought. “

<https://www.hindawi.com/journals/isrn/2014/689826/>

LANGUAGE BARRIERS

[20% of] Americans have problems communicating with their doctors, according to a study from the Agency for Healthcare Research and Quality. That increases to 27% among Asian Americans and 33% among Hispanic people.

Medicare Part B Application Form

DEPARTAMENTO DE SALUD Y SERVICIOS HUMANOS
CENTROS DE SERVICIOS DE MEDICARE Y MEDICAID

Formulario Aprobado
OMB No. 0938-1230
Caduca: 02/2020

SOLICITUD DE INSCRIPCIÓN PARA MEDICARE PARTE B (SEGURO MÉDICO)

1. Número de Medicare

2. ¿Desea inscribirse en la Parte B de Medicare (Seguro Médico)? Sí

3. Su nombre (Apellido, Primer Nombre, Segundo Nombre)

4. Dirección Postal (Número y Calle, Apartado Postal, o Ruta)

5. Ciudad Estado Código Postal

6. Número de teléfono (incluyendo el código de área)
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7. Firma escrita a mano (NO IMPRIMIR)
FIRMAR AQUÍ

8. Fecha de la firma
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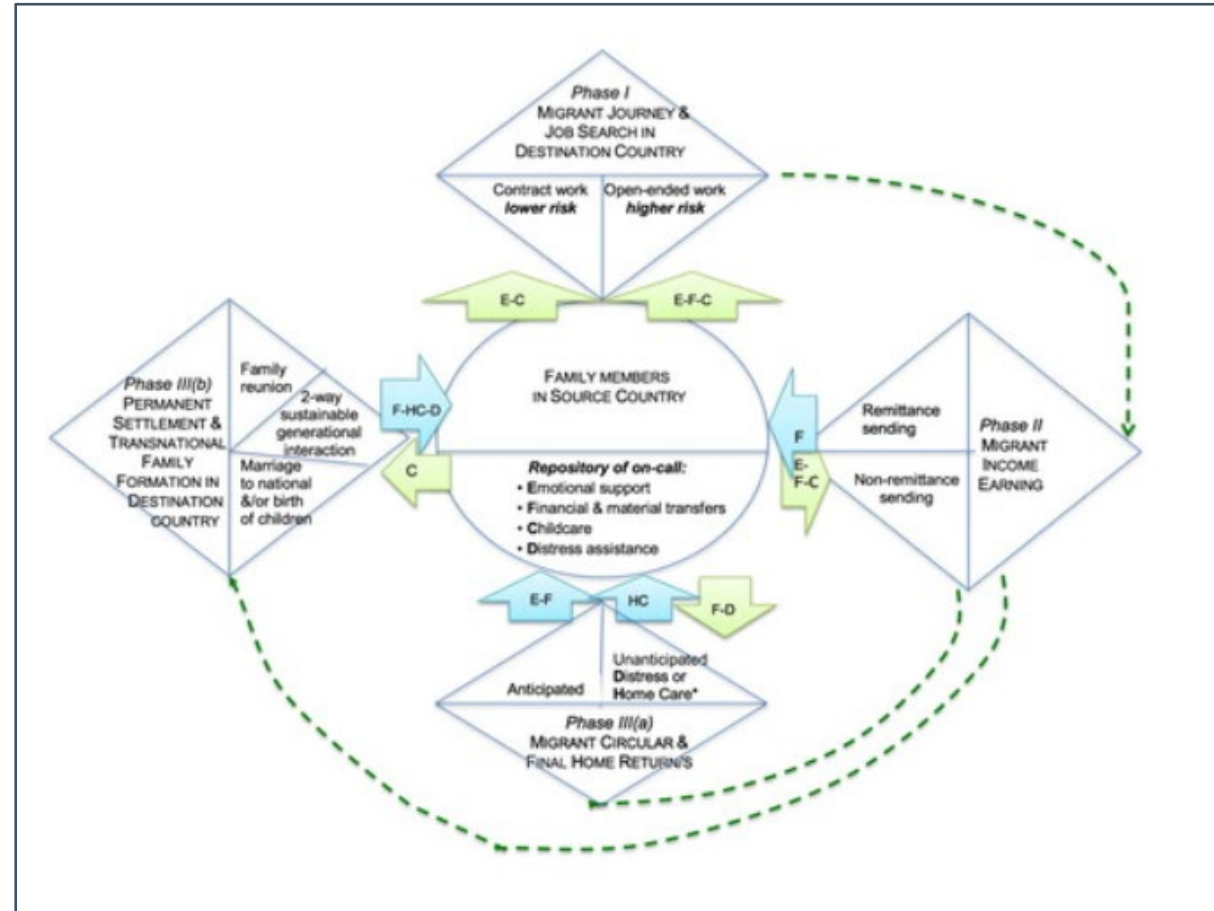
SI ESTA SOLICITUD SE HA FIRMADO CON LA MARCA (X). UN TESTIGO QUE CONOZCA AL

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5094358/>

<https://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/Downloads/CMS40B-S.pdf>

NONTRADITIONAL FAMILY STRUCTURES

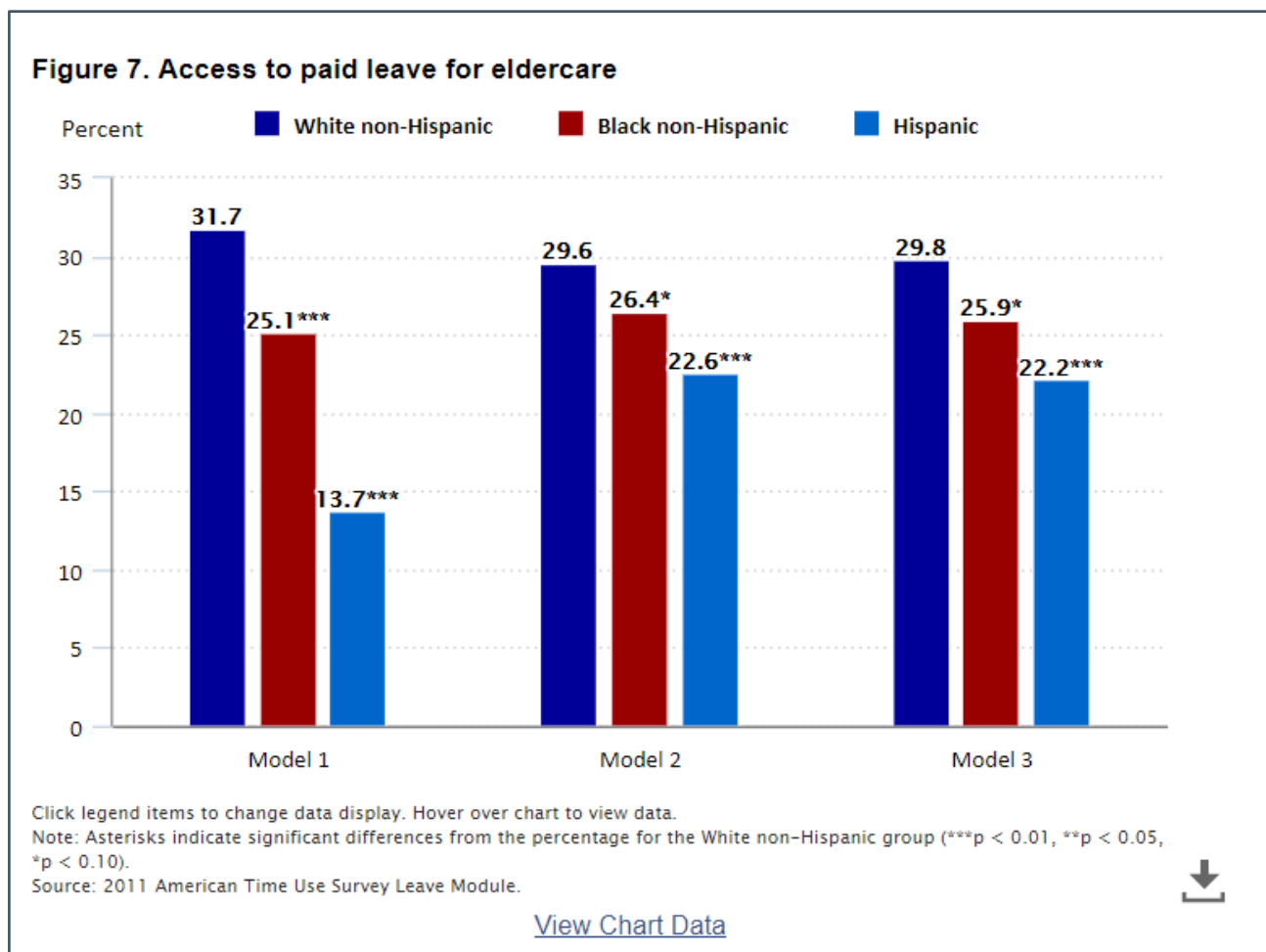
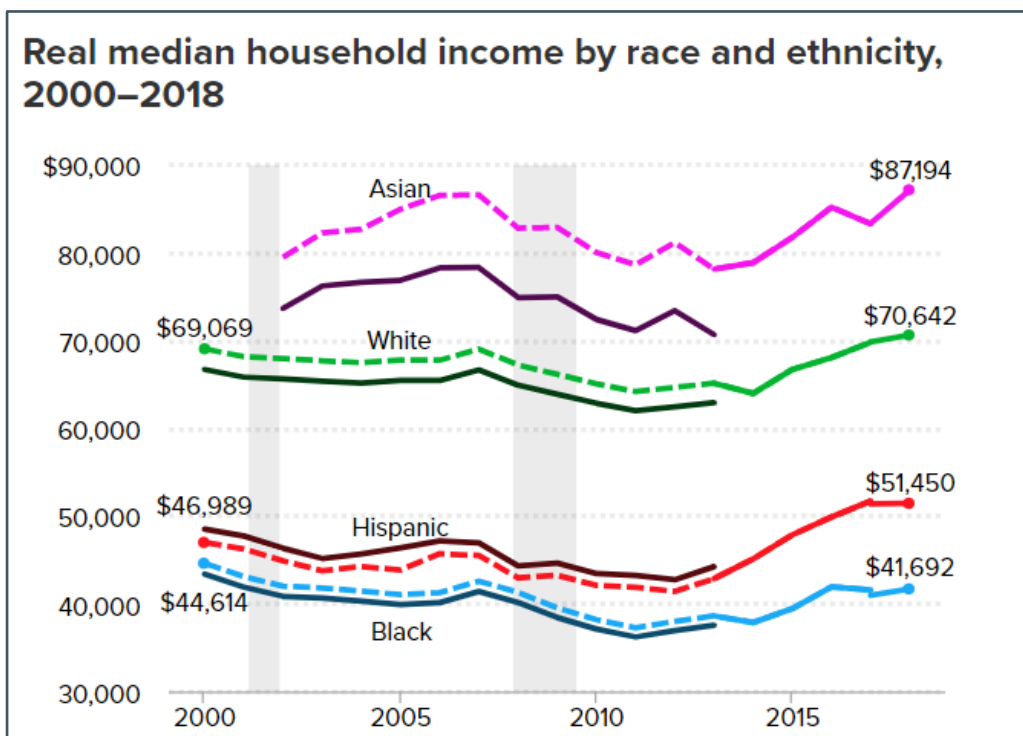
7.8 million children live in grandfamilies, where grandparents or other relatives are the householders



Lofquist, Daphne, Terry Lugaila, Martin O'Connell, & Sarah Feliz. "Households and Families 2010: U.S." 2010 Census Briefs C2010BR-14, U.S. Census Bureau, Washington, DC. 2012. Accessed October 7, 2014 at <http://www.census.gov/prod/cen2010/briefs/c2010br-14.pdf>

Transnational families negotiating migration and care life cycles across nation-state borders by Deborah Fahy Bryceson <https://doi.org/10.1080/1369183X.2018.1547017>

FINANCIAL BURDEN



<https://www.epi.org/blog/racial-and-ethnic-income-gaps-persist-amid-uneven-growth-in-household-incomes/>

<https://www.bls.gov/opub/mlr/2019/article/racial-and-ethnic-disparities-in-access-to-and-use-of-paid-family-and-medical-leave.htm>

ADDITIONAL CROSSCUTTING THEMES

- Navigation of federal/state benefit programs
- Attitudes toward US government
- Cost of aging-in-place
- Fear of discrimination in facilities



KEEP IN MIND

- Distinct/universal
- Cost of unpaid caregiving
- Connection



Elana Kieffer, MBA
ekieffer@nyam.org

@AgeFriendlyNYC

Listening Sessions Presentations



Carol Reagan, MPH
Senior Advisor,
Center for Consumer Engagement in Health Innovation
Community Catalyst

Pamela Nadash, Ph.D.
Associate Professor
Department of Gerontology
McCormack Graduate School
University of Massachusetts



Stakeholder Strategy Sessions

Presentation to the ACL RAISE Family Caregiving
Advisory Council Meeting
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Acknowledgements

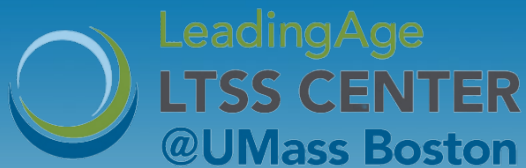
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Presentation Outline

- Purpose of Stakeholder Sessions
- Research Design and Methods
- Action Steps for all Five Goals
- Key Themes and Next Steps
- Discussion

Purpose of Stakeholder Sessions

Ideas and Engagement



Research bridging policy and practice

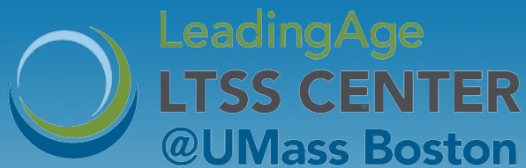


Purpose of Stakeholder Sessions

- Engage insights of key organizations in the work of the Council
- Identify, prioritize and make actionable the specific recommendations that support the Council's five major goals
 - Stakeholders identify preferred action step for each recommendation and discuss what is needed to implement it
- Promote continued participation and involvement as the Council develops its national strategy
- Identify key leaders for the national advocacy work ahead

Research Design and Methods

About the Listening Sessions



Research bridging policy and practice



Online Listening Sessions

- Identified stakeholders and key thought leaders at both national and state levels
- Aimed to reach a range of organizations working on caregiver issues, from aging and disability groups to providers, researchers and other advocates, representing the many faces of caregiving
- 60 groups were invited and 42 participated in six two-hour sessions
- Goal 3 required 2 sessions, given the breadth of that goal and the number of recommendations

Pre-Session Survey

- A short survey was sent out to participants in each group soliciting their initial ideas on key strategies to advance the goals and recommendations
- The feedback was used to facilitate the agenda for the listening sessions
- About half of the participants submitted feedback

Facilitator Goals for the Sessions

- Began with an overview of all five goals and then focused on the session's goal and its recommendations
- Aimed to have open-ended discussion on each recommendation
- Intent was to solicit input on specific strategies to advance the recommendations and consider implementation issues
- Specifically, what actions, policies or programs would be needed; what barriers exist; what timeline is feasible; and what might this cost?

Participants

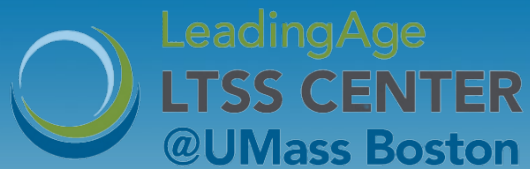
- American Association of Retired Persons (AARP)
- Access Living
- Alzheimer's Association
- American Bar Association
- American Network of Community Options and Resources (ANCOR)
- Association of Programs for Rural Independent Living (APRIL)
- Autism Society of America
- Benjamin Rose Institute on Aging
- Brookdale Foundation
- California Long-Term Care Education Center
- Caregiver Action Network
- Center for Family Support, University of Pittsburgh
- Center to Advance Palliative Care
- Disability Policy Consortium
- Generations United
- Institute for Healthcare Improvement (The Conversation Project)
- Jewish Federation of North America
- Justice in Aging
- LeadingAge
- Little Lobbyists
- Lucile Packard Foundation
- Meals on Wheels America

Participants

- Medicare Rights Center
- Mental Health America
- National Association of Councils on Developmental Disabilities (NACDD)
- National Adult Day Services Association
- National Alliance for the Mentally Ill
- National Asian Pacific Center on Aging
- National Caucus and Center on Black Aging
- National Council on Aging
- National Council on Independent Living (NCIL)
- National Indian Council on Aging
- National PACE Association (NPA)
- National Patient Advocate Foundation
- National Council on Aging (NCOA)
- Scripps Gerontology Center, Miami University
- Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE)
- Sibling Leadership Network
- Institute on Disability and Human Development, University of Illinois
- Southeast Asia Resource Action Center (SEARAC)
- The Arc
- Well Spouse Association

What We Learned

Action Steps



Research bridging policy and practice



Goal 1: Expanded awareness, outreach, and education

- Launch multi-faceted, interagency public awareness campaign showing the many faces of caregiving
- Develop information toolkits and templates for community-level outreach that can be used by CBOs, schools, providers, etc.
- Encourage a collaborative public/private approach
- Use models such as the Medicare Part D campaign to inform planning, cost estimates, and strategies

Goal 2: Family caregiver as key partners with providers

- Synthesize research and create an inventory of caregiver assessment tools
- Develop strategies and mechanisms for systematically involving caregivers in care planning, care teams and in identifying best practices
- Ensure caregivers are identified in electronic health records
- Ensure health and social service staff are educated about the role of caregivers; incorporate caregivers in their training

Goal 3- Access to programs, supports, goods, and services

- Ensure that paid staff are trained to work in a variety of cultural and family contexts
- Increase funding for services and supports - respite, paid caregivers, home modifications, adult daycare, etc.
- Ensure health plans and providers utilize uniform caregiver assessments
- Expand access to health-related services and supports - non-emergency medical transportation, housing, technology and broadband – esp. for low income caregivers

Goal 3 Continued

- Identify effective toolkits and models for quality volunteer programs
- Set up registries to match volunteers with caregivers; use CBOs to promote them
- Involve caregivers in disaster planning (e.g. FEMA) and partner with CBOs doing resiliency training
- Share information on advance directive models
- Increase HCBS funding and make it a required benefit under Medicaid; offer paid leave, hazard pay and career pathways for paid caregivers

Goal 4: Financial and employment security

- Expand access to paid family leave and other forms of social insurance protecting caregivers and care recipients
- Improve financing of LTSS, including federal and state programs; lower or eliminate the 10% threshold for LTSS tax deduction
- Encourage employers to effectively support caregiver employees
 - Support employers in offering flexible workforce policies; identify employer best practices; and educate employers about available caregiver resources
- Disseminate financial planning tools via community and faith-based organizations

Goal 5: Engage caregivers in national research and data gathering

- Conduct a literature review of evidence-based practices in supporting family caregivers and identify gaps in the literature – disseminate via national clearinghouse and database
- Develop a standard set of data elements and definition of caregiver to be included in survey panels
- Create an advisory group of researchers, key organizations with expertise in caregiving - include family caregivers
- Recognize the unique information needs of different types of caregivers

Some Key Themes

Needs for:

- Conducting a major awareness and education campaign about caregiving
- Expanding HCBS and eliminating waiting lists
- Involving a range of stakeholders, including CBOs, healthcare professionals, and employers
- Respecting the broad range of cultures and experiences among caregivers
- Involving caregivers in all aspects of program and policy change
- Broadening technology and broadband access
- Providing systematic access to training and other supports for caregivers
- Improving the wages, benefits, and training of the paid caregiving workforce

2021 Work to Support National Strategy Development

- Engage critical stakeholders for input into and support of the Advisory Council's national strategy and road map
- Conduct 18 key informant interviews and 15 stakeholder listening sessions
- Key stakeholders include employers, CBOs, faith-based communities, direct care workers and others the Council identifies

DISCUSSION

- What additional information would be helpful for your work?
- What are the priority caregiver solutions/domains we should address?
- Who do you want us talking to?
 - Organizations (including those unable to join in December?)
 - Key Leaders
 - Constituencies

Thank you



COMMUNITY CATALYST

Because we all should have a say
in decisions that affect **our health**



LeadingAge
LTSS CENTER
@UMass Boston

Research bridging policy and practice

Break

Initial Report to Congress

Final Review & Discussion

Facilitators:

Nancy Murray, Ph.D.

Casey Shillam, MS

Alan Stevens, Ph.D.

Wrap Up & Next Steps

Greg Link, Director
Office of Supportive and Caregiver Services
Administration for Community Living



Thank you

