



Advancing Caregiver Equity Through Story, Data and Inclusive Policy Tools

On Aging 2026

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Moderator



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Diverse Elders Coalition (DEC)

Learning Objectives

OBJECTIVE 1

Identify evolving caregiving stressors and structural inequities impacting racially, ethnically, and culturally diverse caregivers including LGBTQ+ and immigrant communities.

OBJECTIVE 2

Utilize new tools from the DEC's Caregiving Best Practices Toolkit to incorporate inclusive language, data, and community-led insights into caregiving policy and practice.

OBJECTIVE 3

Understand how storytelling, lived experience, and coalition-building can amplify belonging and drive systems change for caregivers on the margins.

Why now?

Diverse caregivers are central to the care system, but too many remain unseen by policy and underserved by formal systems.

Understanding these evolving factors allows us to better advocate on behalf of all older adults and family caregivers.

Cross-Cutting Inequities

Language Barriers

Mistrust/Discrimination

Mental Health Strain

Fragmented Supports

Research & DEC Toolkit

Over nearly a decade, the DEC's research arc – from multilingual national caregiver surveys and focus groups to updated literature reviews – has helped move that evidence into stronger, community-informed advocacy best practices.



Caregiving Initiative

- 1,100 Respondents
- 36 Focus Groups
- 18 Stakeholder Interviews



Curriculum Development

- COVID listening sessions
- Member expertise in development



Updated Literature Review

- 2025 Literature review to confirm findings
- Inclusion of Direct Care Workers & Intersectionality



Toolkit Development & SAGECare Collaboration

- Updated findings were translated into DEC Policy Toolkit
- Evidence informed DEC collaborative curriculum work with SAGECare to provide education

Speakers



Pedro Lima
Finance and Project Development Manager
National Hispanic Council on Aging (NHCOA)



Anna Byon (They/Them)
Director of National Policy
Southeast Asia Resource Action Center (SEARAC)



Aaron Tax (He/Him)
Managing Director of Government Affairs & Policy Advocacy
SAGE | Advocacy and Services for LGBTQ+ Elders



From Story to System: Caregiving Inequities for Latino Older Adults

- Story from the community – Mr. Enrique Covarrubias
- Supplemental Security Income (SSI) ⇔ Caregiving connection
- What the data confirms
 - Higher unmet needs among diverse caregivers
 - Stress linked to language barriers
 - Lack of culturally and linguistically tailored services
- Key takeaways
- Data ⇔ Story ⇔ Advocacy

From Evidence to Action: NHCOA's Federal Advocacy Approach

- Translating Insight into Policy
 - The role of storytelling in policy advocacy
 - Status of Latino Older Adults Report (SHOAR)
- NHCOA in federal advocacy
 - Hill visits, legislative briefings, legislative breakfasts, etc.
 - Elevating older adult voices through testimonies
- Policy solutions ⇨ DEC Policy Toolkit
- Key takeaways

Southeast Asian American Realities

- SEARAC uses a geopolitical definition of Southeast Asian American: people who are refugees or the descents of refugees from Cambodia, Laos, and Vietnam.
- Resettlement experiences in the U.S. were heavily influenced by escape from war, famine, genocide, political persecution, and family separation.
- ~15,000 SEAs have a final order of removal.
- Intensified immigration enforcement and deportations are harming SEAA families and communities.
 - Fears of interacting with government = underuse of services
 - Prolonged trauma from repeated separation of families and communities



Ways to Advocate for SEAA Communities

SEARAC is calling for:

Ending detentions and deportations

- No funding for ICE and CBP
- No expansion to deportability or inadmissibility
- Protect community spaces and sensitive locations

Supporting SEAA, immigrant, refugee older adults and caregivers

- Provide trauma-informed counseling and mental health supports for caregivers
- Implement trauma-informed care training addressing racism, homophobia, and xenophobia

How can you advocate?

- Engage Congress to stop funding ICE and CBP



LGBTQ+ Community Realities

- Inequities most visible for LGBTQ+ caregivers and older adults
 - Chosen Family not recognized
 - Service mistrust
 - Isolation
 - Formal settings not culturally safe
 - Fear of discrimination
- The role of storytelling in policy advocacy
 - A brief story of an LGBTQ+ older adult

State-level Advocacy in Action

- The importance of state-level advocacy
- State-level policy advocacy advancements through SAGE
 - Long Term Care Bill of Rights
- How SAGECare fits into all of this work
- State-level advocacy takeaways
- The alignment between state and federal level advocacy

Q & A Session



Pedro Lima



Anna Byon



Aaron Tax





DIVERSE
ELDERS
COALITION

Policy Toolkit

Policy Toolkit: Advancing Equity in Caregiving

The DEC developed this comprehensive policy toolkit to translate findings from our latest literature review into actionable guidance for state policymakers and community-based professionals and advocates. Organized around five pillars - Family & Friend Caregivers, Cultural Competence & Intersectionality, Community-based Care, Direct Care Workforce, and Data & Research – the toolkit distills key evidence into concrete policy and practice recommendations. Each recommendation is grounded in peer-reviewed studies and national reports, with references cited throughout so users can trace the underlying research. This toolkit is designed to strengthen equitable, culturally responsive systems of care for diverse older adults and the caregivers who support them.

Family & Friend Caregivers

- **Expand state paid family leave programs to include chosen family caregivers.**
 - Inclusive definitions of family improve caregiver participation among LGBTQ+ and immigrant populations (Fredriksen-Goldsen et al., 2023; AARP, 2023).
- **Establish caregiver stipends or tax credits for unpaid caregivers of color and LGBTQ+ caregivers.**
 - Financial recognition improves health outcomes and reduces reliance on Medicaid long-term care (Morgan et al., 2023; ACL, 2022).
- **Fund caregiver navigation programs through Area Agencies on Aging (AAAs) and CBOs.**
 - Culturally matched navigators reduce care fragmentation and hospital readmissions (Poteat et al., 2024).
- **Create statewide respite voucher programs prioritizing underserved caregivers.**
 - Targeted respite reduces burnout and prevents care breakdowns (Xie et al., 2024; CDC, 2023).
- **Integrate caregiver well-being into Medicaid waivers and care coordination metrics.**
 - States that include caregiver health measures report lower costs and improved patient satisfaction (Lin & Liu, 2022).
- **Develop multilingual caregiver education and resource hubs.**
 - Centralized, language-accessible portals and printed guides improve caregivers' ability to navigate complex systems and claim available benefits.
 - States can partner with community-based organizations (CBOs) to host culturally tailored materials (National Academies of Sciences, Engineering, and Medicine [NASEM], 2022; ACL, 2023).
- **Require health systems to identify and record caregivers during patient intake.**
 - Systematic caregiver identification ensures caregivers are included in care planning, which is essential for elders from collectivist and multigenerational households. (NASEM, 2022; CDC, 2023)

Got Questions?

[DEC Policy Toolkit - bit.ly/DECPolicy_Toolkit](https://bit.ly/DECPolicy_Toolkit)

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