



DIVERSE
ELDERS
COALITION

Aging with Health and Dignity

DIVERSE ELDERS SPEAK UP





Marcos Bautista sending his comments to ACL.

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Executive Summary

In 2016, the Diverse Elders Coalition (DEC) partnered with Caring Across Generations to collect 4,710 comments from older adults, their family members, advocates and allies living in all fifty states, expressing the necessity for federal, state, and local aging policies and programs to assess and meet the needs of American Indian and Alaska Native elders; Asian American, Pacific Islander American, and Native Hawaiian elders; Black and African American elders; Hispanic and Latino/a elders; and lesbian, gay, bisexual, and transgender (LGBT) elders.

Despite differences in race, culture, geography, language, sexual orientation, and gender identity among the communities who submitted comments during this campaign, there were striking similarities among the stories and comments we received. Based on these comments and the common threads running through them, the Diverse Elders Coalition makes the following recommendations to legislators and policymakers as they shape aging programming in the United States, including:

- **Culturally and linguistically competent services for elders;**
- **Greater support for aging-in-place, especially policies that support affordable housing and livable communities in urban and underserved rural areas, including Indian Country, Alaska Native villages, and Hawaiian Home Lands; and**
- **Accurate, disaggregated data collection about our communities.**

In addition to these three recommendations, which were evident in comments from all five of the constituencies served by our coalition members, many other issue areas were raised by individuals and organizations who responded to this call for comments, including but not limited to: access to healthy food, the importance of community-based organizations, and the challenges of aging with HIV. Several significant comments stressed the importance of carrying out federal trust responsibility and treaty obligations to Native American Indians, as described in the U.S. Constitution. We invite you to explore these issues in more depth through the content of this report and its appendices.



The 4,710 comments that the DEC collected were shared with the Administration for Community Living (ACL) to help shape its Guidance for the Development and Submission of State Plans on Aging. As we look beyond 2016 and this public comment period, we recognize that our communities face very real threats to our right to age with health and dignity, and the Diverse Elders Coalition will work tirelessly to ensure that the needs of our communities—and the strength of our collective voice—do not go unnoticed.

The Diverse Elders Coalition would like to thank our community partners who assisted in collecting these comments, without whose tireless work this project could not have been completed. We would also like to acknowledge the generous support from the Ford Foundation and Atlantic Philanthropies in the funding of this campaign, as well as the support from our partners at Caring Across Generations in conceiving and executing this project.

Introduction

What is the Diverse Elders Coalition?

Founded in 2010, the [Diverse Elders Coalition](#) exists to address the profound challenges of aging in underserved populations. We do this by advocating for policies and programs that improve aging in our communities as racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual and/or transgender people.

Together, we are made up of five national organizations representing a growing majority of millions of older people throughout the country. We have come together to promote policy changes and programmatic solutions that respond to this demographic shift and will remove the barriers facing our communities.

Our member organizations include:

- [National Asian Pacific Center on Aging \(NAPCA\)](#)
- [National Hispanic Council on Aging \(NHCOA\)](#)
- [National Indian Council on Aging \(NICOA\)](#)
- [Services and Advocacy for GLBT Elders \(SAGE\)](#)
- [Southeast Asia Resource Action Center \(SEARAC\)](#)

As a coalition, we have significant ties to our communities in hard-to-reach rural areas, cities and regions throughout the U.S. This translates into advocacy efforts that are informed by:

1. Authentic expertise on the challenges diverse elders face
2. The credibility to mobilize diverse elder communities on issues that affect them; and
3. The skills to advance a federal policy agenda that promotes the health, economic security, dignity, and wellbeing of older adults across many different communities, thereby improving outcomes for all older people.

By leveraging the overlapping interests and complementary expertise of our member organizations, we are ideally positioned to address one of the pivotal issues of our time: the aging of a growing, diverse American population.

“Native Elders and their families deserve a better quality of life. It is important that elders access all resources available and have the support needed.”

– SALLY, NEW MEXICO

What is the Administration for Community Living (ACL)?

All Americans—including people with disabilities and older adults—should be able to live at home with the supports they need, participating in communities that value their contributions. To help meet these needs, the U.S. Department of Health and Human Services (HHS) created a new entity in 2012: the Administration for Community Living (ACL).

ACL brings together the Administration on Aging (AoA), the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan.¹

What is the ACL’s guidance?

In June 2016, the Administration for Community Living (ACL)/U.S. Administration on Aging (AoA) announced a public comment period on Guidance for the Development and Submission of State Plans on Aging, State Plan Amendments and the Intrastate Funding Formula. The guidance, in the form of a template program instruction that ACL/AoA staff would complete on an annual basis, would in turn provide the information and guidance on which state units on aging would rely to develop state plans as required under the Older Americans Act.

To read the June 2016 template in its entirety, visit http://www.aoa.acl.gov/AoA_Programs/OAA/Aging_Network/pi/docs/template-PI.pdf

The Diverse Elders Coalition partnered with [Caring Across Generations](#) to mobilize our communities to respond to ACL’s guidance template and ensure that diverse elders’ needs are met by the ACL and the aging network.

¹http://www.acl.gov/About_ACL/index.aspx

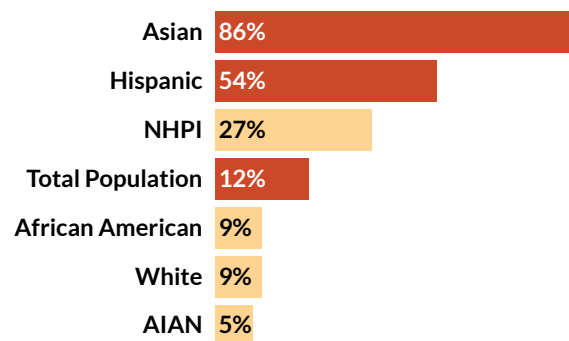
Comments and Recommendations

During the 60-day comment period, the Diverse Elders Coalition and its partners collected and submitted 4,710 comments in six languages, including English, Spanish, Chinese, Korean, Vietnamese, and Hmong. Comments were received from all 50 of the United States.

CULTURALLY AND LINGUISTICALLY COMPETENT SERVICES

Despite differences in race, culture, geography, language, sexual orientation, and gender identity among the communities who submitted comments during this campaign, there were striking similarities among the stories and comments that were shared with the Diverse Elders Coalition. The desire for culturally competent services, especially those offered in an elder’s native language, were a key finding from all five of our coalition members’ comments. Asian American and Hispanic older adults —many of whom are foreign-born and speak English as a second language—are underrepresented in those seeking social services, such as programs funded by the Older Americans Act (OAA), even though there is ample data indicating that their need for these services is greater than that of the older American population in general. Translation needs are also significant in American Indian/Alaska Native (AI/AN) communities, where many of the elders continue to use Native languages to communicate.

Percent of Population who are Foreign-born* by Race and Hispanic Origin, 65 Years and Older



* According to the U.S. Census Bureau, the term “foreign-born” refers to anyone who is not a U.S. Citizen at birth. An individual who is “native-born” was born in the United States, Puerto Rico, a U.S. Island Area (including American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, or the U.S. Virgin Islands), or abroad to U.S. citizen parent(s). Source: U.S. Census Bureau, 2009-2011 American Community Survey (ACS), 3-Year Estimates

“We need simple explanations and easy ways to fill out applications and documents related to social services.”

– ANGEL, NEW JERSEY

The comments from our community members reflect a gap in awareness of the availability of these programs, an inability to apply for or get information on these services in native languages, and the lack of assistance to read mail, fill out paperwork, or get transportation to appointments. Comments from Asian American and Pacific Islander American (AAPI) older adults overwhelmingly spoke of difficulty understanding and being understood by automated telephone menus, through which many essential social services are accessed. Over 85% of Southeast Asian American elders have limited English proficiency, and services are often not available to them in their native languages.²

Although American Indian/Alaska Native languages are seldom written, many languages are still spoken. More than one in five AI/AN adults aged 65 and over reported speaking a Native language at home or in their communities³ but those languages are rarely offered in governmental programs. The language access needs of diverse elders point to the importance of community-based organizations and providers to ensure that those in our communities understand the services that are available to them.

The need for cultural competence extends beyond just language. Lesbian, gay, bisexual, and transgender (LGBT) elders commented in large numbers about the fear of “going back into the closet” in retirement communities and healthcare facilities, fearing homophobic and transphobic staff and residents. American Indian and Alaska Native community members wrote about the challenges of living in deeply rural areas of Indian Country where distance

² <http://napca.org/wp-content/uploads/2013/10/55+-population-report-FINAL.pdf>

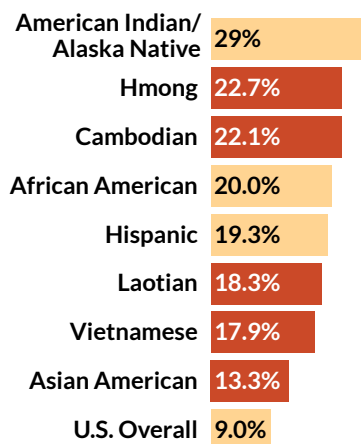
³ <http://www.census.gov/prod/2011pubs/acsbr10-10.pdf>

and access to services leaves elders and community members unserved or underserved. It is not unheard of in Indian Country to have communities that still do not have access to running water, electricity, or simple internet or cell phone service. Hispanic elders wrote about the importance of *la familia* and the value of including multiple generations of the family in the care and support of Latino older adults. Asian American and Pacific Islander American elders wrote about the need for comprehensive services based in their communities and delivered by trusted community-based organizations who understand and share their unique linguistic and cultural needs. It is essential to the health, wellbeing, and dignity of our communities that the staff providing healthcare and social services to diverse elders have undergone cultural competency training for the populations they serve; even better if these providers are members of the communities themselves.

HOUSING

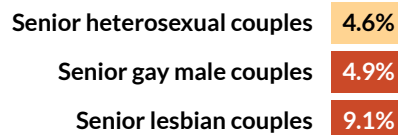
Many of our communities' comments also reflected the growing need for safe, accessible, affordable housing. Poverty rates among diverse elders are higher than those in white and/or heterosexual and cisgender⁴ communities, and many, including LGBT older adults, face pronounced discrimination in the housing market.⁵ Thus, diverse older adults often struggle to find housing they can afford in the communities they call home.

Poverty Rates for Individuals 65 and Over



Sources: US Census 2010, AARP, National Research Council

Poverty in the LGBT Community



Source: Goldberg, Naomi G. "The Impact of Inequality for Same-Sex Partners in Employer-Sponsored Retirement Plans," The Williams Institute, May 2009.

As the elders in our communities get older, many want to age in place but lack the resources to modify their homes to be age-friendly; additionally, communities may lack transportation and accessibility options that allow elders to remain at home. However, when those older adults are then relocated to senior housing and eldercare facilities, many encounter unwelcoming or hostile environments. LGBT older adults wrote about this fear in hundreds of comments submitted to the Diverse Elders Coalition. After overcoming lifetimes of discrimination based on their sexual orientation and/or gender identity in order to finally live proudly as who they are, the last thing LGBT elders want is to have to hide those identities from the staff and peers at senior centers, senior housing, and care facilities. Will they have to pretend that their same-sex partner is a brother or sister? Will they have to express their gender in a way that feels uncomfortable or unnatural to them? LGBT older adults are in greater need of services and supports, but less likely to engage the services and supports provided by the Older Americans Act, due in no small part to fear of discrimination.⁶

American Indian/Alaska Native elders also wrote in their comments about the high rates of poverty and unemployment in their communities, both in Indian Country and in rural areas. If an AI/AN elder has been un- or underemployed for a majority of his adult life

“There’s the stereotype that gay people are all affluent. Truth is, most of us have led a hard life because of discrimination and lack of support. It’s sad that many of us who fought so hard for liberation are now alone, forgotten and barely surviving.”

- ARTHUR, NEW YORK

⁴ A person whose sense of gender identity matches their gender assigned at birth. See: <http://www.advocate.com/politics/transgender/2015/06/25/cisgender-added-oxford-english-dictionary>

⁵ <https://www.sageusa.org/newsevents/release.cfm?ID=89>

⁶ <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>; <http://www.aarp.org/relationships/family/info-04-2011/biggest-issues-facing-older-lgbt-americans.html>

—and is also supporting children or grandchildren—how will he be able to afford to retire? How will she continue to pay the costs of daily living? Hispanic older adults and AAPI older adults—as well as their family members—expressed similar concerns about economic security and housing as they age. The Older Americans Act and services provided by the ACL have an enormous impact on diverse elders’ ability to find and keep housing, including meal delivery services, transportation, nursing home protections, and guidance for helping older adults age in their homes.⁷ These services must acknowledge and incorporate the unique needs of elders of color, American Indian/Alaska Native elders, and LGBT elders at the Federal, state, and local levels.

DATA COLLECTION

A final common recommendation from the comments collected during this campaign is the collection and analysis of disaggregated data about our communities. The standards for maintaining, collecting, and presenting Federal data on race were last updated in 1997. At that time, respondents to federal data collection measures were offered the option of selecting one or more racial designations, and a number of new categories were created, including “African American” and “Native Hawaiian or Other Pacific Islander.”⁸

While we applaud the expansion of these data categories in 1997, these standards have enormous room for improvement today, and the absence of more specific categories about our communities’ race and ethnicity measures have meant that many diverse elders have fallen through the cracks. For example, NAPCA tracks the existence of 25 unique Asian American and Pacific Islander subgroups, the members of which speak over 40 different languages and dialects.⁹ There are vast differences among these groups in terms of their English proficiency, countries of origin, access to education, and poverty, and by choosing not to collect data on their specific populations, the ACL and other agencies are missing out on a vital opportunity to better meet their needs. To this point, we recommend that governing agencies include a maximum number of race data elements when surveying constituents.

“Data is so important for planning programs and services. Current ‘Asian’ data is useless because it doesn’t count the huge variety of culture and language in AAPI.”

– ANDREA, WASHINGTON

Furthermore, it’s only in recent years that Federal support has increased for collecting data on LGBT identities. Agencies like the US Department of Health and Human Services and the CDC have begun including questions about sexual orientation and gender identity on some of their surveys,¹⁰ but others like the US Census do not. This means that data is incomplete or unavailable on the numbers of LGBT older adults in each community, requiring the use of other methodologies or proxies to assess and meet their unique needs. Absence of data on sexual orientation and gender identity also allows providers to perpetuate the untrue notion that they do not serve LGBT clients, when it is generally understood that LGBT people live—and access services—in every county in the United States.¹¹

OTHER COMMUNITY CONCERNS

Many other issue areas were highlighted in our communities’ comments, including the need for increased access to healthy, nutritious food; the importance of carrying out federal trust responsibility and treaty obligations to Native American Indians; and the challenges of aging with HIV. In the appendices to this report, you can read the organizational comments that were submitted by each of the Diverse Elders Coalition members, which encapsulate the needs that are common to several of our constituencies as well as those that are unique to each.

⁷ <https://www.whitehouse.gov/blog/2016/04/21/reauthorizing-older-americans-act-protect-our-citizens>

⁸ <https://www.federalregister.gov/documents/2016/09/30/2016-23672/standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity>

⁹ <http://napca.org/wp-content/uploads/2013/10/55+-population-report-FINAL.pdf>

¹⁰ <http://www.hhs.gov/programs/topic-sites/lgbt/better-information/index.html>

¹¹ <http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/lgbt-demogs-sep-2014/>

Appendices

The following appendices provide more research and support for the content of this report and the policy recommendations made by the Diverse Elders Coalition.



Maxine Garcia, NICOA SCSEP participant, mailing her comments to ACL.

Official organizational comments from all five coalition members

[NAPCA Official Comment to ACL](#)

[NHCOA Official Comment to ACL](#)

[NICOA Official Comment to ACL](#)

[SAGE Official Comment to ACL](#)

[SEARAC Official Comment to ACL](#)

[#TellACL Comment Cards](#)

[SAGE organizational sign-on letter](#)

[NHCOA infographic](#)

[SAGE infographic](#)

[SEARAC infographic](#)

[NAPCA video: Growing Population of AAPI Older Adults](#)

[Storify transcript of #TellACL Twitter chat](#)



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