A Seat at the Table:
Diverse Elders Engage the
2015 White House
Conference on Aging

2015 REPORT
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The White House Conference on Aging (WHCOA) has happened once a decade since 1961 as a rare opportunity to focus the nation’s attention on the needs of our elder population. This year, the White House Conference on Aging comes at a particular moment in our nation’s history that uniquely speaks not only to the needs of elders of color and LGBT elders, but also to their resilience and the role they have played in building our nation. This generation of diverse elders grew up in a time of social upheaval and fought for civil rights and equality in the 1960s and since. They came to the United States from a broader array of nations as our immigration laws equalized access to visas for nations outside of Europe. They were born as federal law and policies shifted and loss of native land and economic hardship instigated the relocation of American Indians/Alaska Natives out of reservations and into urban areas. They took care of their own in the 1980s and for thirty years since, in response to the evolving HIV/AIDS epidemic, relentlessly fighting for health care and equal treatment under the law regardless of sexual orientation or gender identity.

These are the elders the Diverse Elders Coalition (DEC) and its member organizations serve, and whose voices we bring to the 2015 White House Conference on Aging. Our five member organizations, in their decades of service to elders of color, indigenous elders, and LGBT elders, are no strangers to engaging the White House and other policymakers on the issues that matter to our constituencies. It is therefore no surprise that individually and collectively, as a coalition, we bring our communities’ voices and our advocacy expertise to this year’s White House Conference on Aging and the various activities that have led up to the July 13 main event.

This report documents the work we have done over the past year to ensure that the voices of diverse elders are heard and that their unique perspectives and needs are addressed in the policies that are put forth. As individual members, we made specific recommendations on policies, participants, and procedures to the White House Conference on Aging to maximize our communities’ engagement. As a coalition, we provided critical feedback to the White House Conference on Aging in their efforts to be as inclusive as possible. In the pages that follow, we share the recommendations that we have made in the common goal of making the White House Conference on Aging an event for ALL elders and recommit to ensuring that our communities’ voices are heard.

The work we have done hits a crescendo here as we take full advantage of this moment when the nation’s attention is most focused on our elders. But we know that the most important work happens not on July 13, but in the days, weeks, months, and years to follow as we continue to build on the policy victories we have helped secure to guarantee that the promises of aging in dignity and security are kept not just for a select few, but for all of us. The Diverse Elders Coalition is dedicated to seeing this vision come into fruition in the upcoming decade.

We want to close by thanking DEC staff, member organizations, and partners who made the work we document here possible. Working with our friends and colleagues around the country at both national and local levels has been critical to making sure that unheard voices are heard. We also appreciate Verizon’s financial support of our work. We look forward to strengthening our relationships and forging new partnerships as our work on behalf of diverse elders builds off of the White House Conference on Aging into the next ten years.

Sincerely,

Diverse Elders Coalition
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)
ABOUT THE DIVERSE ELDERS COALITION

Founded in 2010, The Diverse Elders Coalition (DEC) exists to address the profound challenges facing older people of color, American Indians/Alaska Natives, and LGBT people. We do this by advocating for policies and programs that improve aging in our communities. We stay on the pulse of key policy debates on aging to educate and connect our older people and their loved ones to these debates, while also increasing public support for issues that affect our communities.

Our member organizations—National Asian Pacific Center on Aging (NAPCA), National Hispanic Council on Aging (NHCOA), National Indian Council on Aging (NICOA), Services & Advocacy for GLBT Elders (SAGE), and Southeast Asia Resource Action Center (SEARAC)—are influential players in the federal advocacy arena and experts in the distinctive needs of the racial, ethnic, and cultural communities they represent. Together, we have an unusual degree of access to our communities in rural areas, cities and regions throughout the U.S. This unique connection with diverse communities 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 agenda that promotes the health, economic security, dignity, and well-being 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 deal with the pivotal issues of our time.

ABOUT THE WHITE HOUSE CONFERENCE ON AGING

The White House has held a Conference on Aging each decade since the 1960s to identify and advance actions dedicated to improving the quality of life of older Americans. The 2015 White House Conference on Aging is an opportunity to look ahead to the issues that will characterize the landscape for older Americans for the next decade. This year, the WHCOA will mark the 50th anniversary of Medicare, Medicaid, and the Older Americans Act, as well as the 80th anniversary of Social Security. The 2015 White House Conference on Aging is an opportunity to recognize the importance of these key programs as well as to envision the future.

In the months leading up to the July event, the White House Conference on Aging has been collecting input and feedback from Americans about how to shape the aging policy landscape through a number of venues, including its website, social media, listening sessions with stakeholders and regional forums across the country in Florida, Arizona, Washington, Ohio, and Massachusetts. This year’s White House Conference on Aging focuses on four policy areas: Healthy Aging, Long-Term Services and Support, Retirement Security, and Elder Justice.
The Diverse Elders Coalition and its members engaged the White House Conference on Aging on a variety of fronts. From working with the WHCOA organizers to open up additional opportunities in its planning process to engage diverse communities, to making recommendations for participants and speakers at White House Conference on Aging events, to providing policy analysis and recommendations for specific policy changes to improve the lives of diverse elders, the DEC worked diligently to make sure the voices of its constituencies were heard.

Some direct outcomes from this engagement include:

- The Diverse Elders Coalition submitted its “Principles of Inclusion and Engagement” (See attached exhibit) with specific recommendations to improve outreach to diverse communities. At least three presenters recommended by the Diverse Elders Coalition and its members took part in WHCOA Regional Forums. Seven additional events were held by the DEC and its member groups to create new opportunities to bring even more diverse voices to the White House Conference on Aging.

- DEC and its members provided extensive lists of elders, advocates, and providers from diverse communities to both the White House Conference on Aging, and its key partner, the Leadership Council on Aging. Despite issues such as geographic isolation and technological barriers, many participants were able to take part in White House Conference on Aging Regional Forums. In Cleveland, for example, thanks to active engagement from contacts through the White House Initiative on Asian Americans and Pacific Islanders, a significant number of AAPI participants were able to participate.

- Working with the Leadership Council on Aging, DEC members participated in developing their set of policy recommendations. Specific policy recommendations from the DEC (See attached exhibit) and its members were also presented directly to the White House Conference on Aging. The DEC’s response to the White House Conference on Aging’s Policy Briefs focused on Data and Research, Cultural and Linguistic Competence, and Non-Discrimination and Equal Treatment Under the Law. In response to a request from White House Conference on Aging staff, the DEC submitted an addendum (See attached exhibit) that provided more information and specific policy recommendations. The DEC considers the implementation of these recommendations in the discussions at the Conference as a key metric to gauge the administration’s commitment to diverse elders.

The DEC member organizations plan on engaging the White House Conference on Aging as participants at the July 13th event itself, as well as through viewing parties with our local partners around the country. The principles of inclusion, the voices of the constituents our member organizations serve, and the policy recommendations we have made form the basis on which we measure progress at the White House Conference on Aging and how we will evaluate its impact on our communities.

On July 14, the 50th anniversary of the Older Americans Act, the DEC will be joined by Rep. Mark Takano (D-CA) for a Congressional Briefing to talk about diverse elders, the findings in this report, and next steps for the next ten years as the 2015 White House Conference on Aging closes.
In September 2014, DEC members met with Nora Super, the newly installed Executive Director of the White House Conference on Aging, and Kathy Greenlee, the Administrator for the Administration on Community Living to discuss the White House Conference on Aging and how it can be most responsive to the needs of elders of color, American Indian/Alaska Native elders, and LGBT elders, all of whom have been traditionally neglected by public policy.

Over the next several months, DEC member organizations and staff continued to engage the White House Conference on Aging in its planning process. In a departure from previous years where White House Conferences on Aging were large central events whose participants were drawn from an extensive process of nominations and vetting, the 2015 White House Conference on Aging went out across the country and held five regional Forums in Tampa, FL, Phoenix, AZ, Seattle, WA, Cleveland, OH, and Boston, MA. The DEC staff and member organizations worked closely with the Leadership Council on Aging, the leading national coalition of aging advocacy organizations, to recommend participants and speakers to the Regional Forums and the main conference, as well as providing coalition-wide policy recommendations.

Presenters recommended by the DEC at the Regional Forums included:

- Diane Narasaki from Seattle’s Asian Counseling and Referral Services spoke at the main Plenary at the April 2nd Seattle Regional Forum
- Dr. Jeanette Takamura, former Assistant Secretary for Aging at the U.S. Administration on Aging
- DEC National Managing Coordinator Ben de Guzman was invited to report the results of the Elder Justice breakout group discussion at the Seattle Regional Forum

DEC staff and member organizations also maintained direct communication with the White House Conference on Aging, providing feedback and recommendations directly to White House Conference on Aging staff. The White House Conference on Aging proactively reached out to the DEC and its member organizations as a resource in its effort to reach communities of color, immigrants, AI/AN elders, and LGBT people. An unintended consequence of this is a “cycle of mutual neglect” where decision makers don’t get to hear from communities and thus don’t speak to them, and the communities whose voices aren’t heard get the message that their voices don’t count.

—DEC Principles of Inclusion and Engagement

As the saying goes, “if you don’t have a seat at the table, chances are you’re on the menu.” The over-reliance on “the usual suspects” and staying within traditional networks leaves out under-served communities such as communities of color, immigrants, AI/AN elders, and LGBT people. An unintended consequence of this is a “cycle of mutual neglect” where decision makers don’t get to hear from communities and thus don’t speak to them, and the communities whose voices aren’t heard get the message that their voices don’t count.
the widest possible audience. In January 2015, the DEC issued its “Principles of Inclusion and Engagement” (See attached exhibit) that made specific recommendations on best practices for culturally and linguistically competent programming.

**Recommendations included:**

- Addressing geographic diversity and reaching out to areas beyond the five Regional Forums;
- Improving data collection to make sure that the best information about diverse constituencies is available;
- Increasing linguistic access for participants with limited English proficiency;
- Establishing culturally competent practices that address the needs of as diverse a constituency as possible; and
- Ensuring that technology is a means to extend the conference’s reach, instead of a gatekeeper that prevents community members with varying levels of access from meaningful participation.

Additionally, the DEC and its members worked with the White House Conference on Aging to hold specific events and listening sessions to bring voices of diverse elders directly to Executive Director Nora Super and other White House Conference on Aging team members:

**February 10, 2015:** SAGE held a listening session with Executive Director Nora Super and Administrator Kathy Greenlee as part of a National LGBT Elder Housing Summit in collaboration with the White House Office of Public Engagement. Over 100 participants provided feedback to the White House on housing needs for LGBT elders.

**April 1, 2015:** DEC and NAPCA participated in a site visit to Seattle’s Asian Counseling and Referral Services in collaboration with the White House Conference on Aging and the White House Initiative on Asian Americans and Pacific Islanders. Local leaders from the Asian American and Pacific Islander (AAPI) community provided information about their elder populations and the issues they face.

**May 6, 2015:** The White House Conference on Aging and the Administration on Community Living, in partnership with the National Indian Council on Aging hosted a Tribal Listening Session in Norman, Oklahoma. The Session featured Administrator Kathy Greenlee and ACL Director of American Indian/Alaska Native/Native Hawaiian Programs Cynthia LaCounte. Over 100 representatives from tribes across Indian Country shared their stories about their experiences on a variety of issues.

**May 7, 2015:** DEC staff and member organizations, including NAPCA, SEARAC, and NHCOA, led a diverse host committee of national and local organizations in putting on a Town Hall of diverse elders to bring voices from a variety of constituencies to the White House Conference on Aging in Los Angeles, CA. Caregivers, service providers, advocates, and elders provided personal testimonies to Executive Director Nora Super. Simultaneous translations were conducted in Spanish and Khmer at the event, which was hosted by the Pilipino Workers Center of Southern California, a member of the Caring Across Generations Campaign.

**RELATED DOCUMENTS**

- DEC Media Advisory and Release, Los Angeles Town Hall
- DEC Flyer, May 7 Town Hall
- SAGE Document, "Taking Our Housing Initiative to the White House"
- NICOA Flyer, May 6 NICOA Oklahoma Listening Session
- NICOA News Release, May 6 NICOA Oklahoma Listening Session

*All documents are available at diverseelders.org/learn*
The Diverse Elders Coalition’s member organizations bring decades of direct engagement with elders of color, American Indian/Alaska Native elders, and LGBT elders. As a trusted partner and advocate for these communities, the DEC was a vital resource to help the White House Conference on Aging connect with diverse constituencies. The DEC provided an extensive list of individuals from the communities its members serve to both the Leadership Council of Aging Organizations and to the White House Conference on Aging directly. Representing elders, advocates, service providers, and policy experts, this list reflected a diverse cross-section of our communities. The White House Conference on Aging’s logistics and limited bandwidth presented challenges in bridging the gap between intention, invitation, and participation. In addition to lack of ample time, technological barriers such as limited e-mail access and old computers, often prevented elders—most of whom come from diverse backgrounds—from full participation. Budgetary constraints also posed a challenge in connecting leaders from communities to attending Regional Forums that were often still far away from their locations.

One success story came out of Cleveland, where local partnerships in the AAPI community between the DEC, local organizations, and governmental liaison outreach offices allowed a coordinated effort to make sure that leaders from the AAPI community across Ohio were identified, recommended, and prepared to participate in the Cleveland Regional Forum. Anecdotal reports from the Forum estimated about 20% of the audience of 200 coming from the AAPI community.

It is these kinds of stories that drive DEC’s mission in ensuring that diverse elders, who are often left out and unheard, not only have equal access to opportunities but also have their voices elevated. These are the voices the Coalition looks forward to hearing more of at the White House Conference on Aging.

**RELATED DOCUMENTS**

- DEC Principles of Inclusion and Engagement
- NHCOA 2014 Report: Status of Hispanic Older Adults: Stories from the Field
- SAGE WHCOA Engagement Guide
- WHCOA Blog Post “Celebrating Diversity”

All documents are available at diverseelders.org/learn

**MAKING CONCRETE IMPROVEMENTS IN DIVERSE ELDERS’ LIVES**

Recommendations to the White House Conference on Aging on policies to make concrete improvements in the lives of elders that respond to the unique challenges and disparities in communities of color and for LGBT people came both from individual member organizations of the DEC and as a coalition. Policy recommendations from member organizations were able to identify specific policies across a range of federal agencies that could either be changed, eliminated, improved, or introduced as new policy.

The Diverse Elders Coalition also provided policy recommendations to the White House Conference on Aging as a collective. The White House Conference on Aging issued four Policy Briefs that corresponded to the four policy areas of focus: Healthy Aging, Retirement Security,
Long Term Services and Supports, and Elder Justice. The Policy Briefs only made cursory mentions of elders of color and American Indian/Alaska Native elders, and made no mention of LGBT elders at all. The DEC Response to the White House Conference on Policy Briefs noted this and demanded more intentional inclusion of our communities. DEC’s policy recommendations focused on three overarching issues:

• **Data and Research** – The DEC calls for the White House Conference on Aging to gather best practices in terms of data collection and disaggregation and to employ them in research done to inform policy initiatives.

• **Cultural and Linguistic Competence** – The DEC urges the White House Conference on Aging to identify the best practices to provide culturally and linguistically appropriate services to all elders and commit to implementing them across the board.

• **Non-Discrimination and Equal Treatment Under the Law** – The policies that are intended to benefit all elders must be as inclusive as possible and contain the strongest language available around non-discrimination and equal treatment.

In response to a request from White House Conference on Aging staff to provide more feedback and specific examples of policies, the DEC released an addendum that provided more specific policy analysis and recommendations:

• **Data and Research** – The DEC referred to recommendations from SEARAC and SAGE around disaggregated data, cross-tabulations of data, and data collection on sexual orientation and gender.

• **Cultural and Linguistic Competence** – The DEC referenced the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care as a minimum baseline to measure competence for services geared towards elder populations. The DEC additionally referred to SAGE’s recommendations that the unique cultural needs of LGBT elders specifically be addressed by agencies such as State Units on Aging, Area Agencies on Aging, and HUD programs that provide housing for LGBT elders.

• **Non-Discrimination** – Elders of color and LGBT elders face discrimination based on a variety of factors, including: sexual orientation, gender identity, citizenship status, and political relationship to the U.S. government for Native tribes and Pacific Island jurisdictions. Religious discrimination is even allowed in certain circumstances, including in the interest of national security (which is not defined clearly) and in the evolving discussion around religious freedom for people who disagree with marriage equality. Executive action to prevent these types of discrimination is needed.

The White House Conference on Aging is expected to announce new policy initiatives and the Diverse Elders Coalition and its member organizations look forward to the outcomes from the conference in comparison to the policy recommendations we have provided.

**RELATED DOCUMENTS**

• DEC Policy Recommendations
• DEC Policy Recommendations: Addendum
• NHCOA Policy Brief Response
• NAPCA Policy Brief Response
• NAPCA Director Wes Lum’s Policy Brief Response
• SAGE Policy Brief Response
• NICOA and NMCOA Policy Recommendations

All documents are available at diverseelders.org/learn
On July 13, the White House Conference on Aging is expected to bring together 200 people from around the country for its culminating event at the White House. President Obama and leading elected officials, policymakers, and advocates are expected to join elders from across the country to discuss the state of affairs for Older Americans and to announce new policy initiatives to improve their lives and their communities. Local events around the country are expected to livestream the proceedings on the internet and host “viewing parties” to expand the reach of the Conference.

The Diverse Elders Coalition and its member organizations expect to be fully engaged in these activities. DEC member organizations are participating in the White House Conference on Aging as invited attendees. They attend on behalf of our diverse communities, making sure that elders of color, American Indian/Alaska Native elders, and LGBT elders have a seat at the table to be heard and addressed. The coalition member organizations are also hosting local viewing parties and will concurrently cover the day’s activities through social media. The Diverse Elders Coalition is fully committed to participating in the day’s events and connecting the Conference to its constituencies, who are typically neglected and silenced.

This report, as a document of our work to engage the White House Conference on Aging, will be available at the event itself and for the local viewing parties our member groups are hosting in areas such as Seattle, Los Angeles, New York, Albuquerque, and Washington, DC. The diverse voices we have brought together, and the policy recommendations that we make here will be shared with the President and other policymakers to make sure our communities are heard. They form the basis against which we measure any progress the White House Conference on Aging makes.

On July 14, we will cohost a briefing with Congressman Mark Takano (D-CA) and the Congressional Asian Pacific American Caucus. DEC staff and Principals of its member organizations, along with Congressman Mark Takano and other invited guests, will share their observations of the White House Conference on Aging and start to lay out a road map of where we go from here. The unique needs diverse elders have, the sharp disparities they face in a variety of outcomes, and the resilience and survival strategies they have developed will shape the road we take on their behalf. The Briefing will also reflect on the Conference itself, ensuring that concrete commitments to change are fulfilled. To this end, the Diverse Elders Coalition looks forward to continuing to engage the White House, Congress, and other policymakers at federal and local levels to effect the change our constituencies and our communities need, and deserve.
Since 2010, members of the Diverse Elders Coalition (DEC) have played a leading role in articulating the needs and challenges of elder communities that do not often get heard in policy debates, including elders of color, American Indian/Alaska Native (AI/AN) elders, and LGBT elders. The collective experiences these organizations have directly working with a broad cross-section of elder communities, often among the most disenfranchised among them, give DEC members an authoritative voice to speak individually and collectively about how best to engage diverse elder communities.

The DEC member organizations include:

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

In anticipation of the White House Conference on Aging (WHCOA), the DEC and its members have prepared the following set of recommendations to increase inclusion and engagement for diverse communities of elders. In our experience, these practices reflect lessons learned in how to ensure that those who are often the most disenfranchised can best claim their seat at the table.

**INCLUSION**

As the saying goes, “if you don’t have a seat at the table, chances are you’re on the menu.” The overreliance on “the usual suspects” and staying within traditional networks leaves out underserved communities such as communities of color, immigrants, AI/AN elders, and LGBT people. An unintended consequence of this is a “cycle of mutual neglect” where decision makers don’t get to hear from communities and thus don’t speak to them, and the communities whose voices aren’t heard get the message that their voices don’t count.

The DEC members represent constituencies whose perspectives have not historically been a part of policy discussions about aging. Direct outreach to the DEC and to these members will help make sure that participants to the White House Conference on Aging and related events represent as diverse a cross-section of the population as possible.
Additional factors to consider when working to maximize inclusion for diverse elders are:

**Geography** - The regional events leading up to the WHCOA are spread out across the continental United States (CONUS), but are in metropolitan areas that are sometimes not easily accessible to rural populations. The cities selected for the five regional events exclude HHS regions 6, 7, and 8, which contain a large proportion of Indian country. Additionally, locations outside CONUS include populations that are particularly hard to reach, including Alaska Natives, Native Hawaiian, and Pacific Islanders. Special consideration on how to ensure voices from these regions will be heard, either through special consideration for invitations and/or additional support needed to make sure people are able to travel to the cities where events will be held.

**Data Collection and Disaggregation** - Another means by which disenfranchised communities remain so is by lack of data. Insufficient data about communities creates its own self-fulfilling prophecy, where longitudinal data relies on traditional data sets that have excluded certain populations and discourages reconfiguring data samples to include new or different communities. Additionally, data collected in the aggregate often masks specific trends and disparities that can be present in sub-sections of larger communities. For example, things such as the “model minority myth” in the Asian American community are perpetuated by data in the aggregate that reports successful outcomes in total, but hides the realities of underresourced and underachieving refugee communities from Southeast Asia, as well as Native Hawaiian and Pacific Islander communities. Additionally, data collection for LGBT populations has historically been a challenge. The DEC strongly recommends using some of the best practices around data collection and disaggregation, including over-sampling vulnerable populations, and following some of the LGBT data collection strategies proposed by the Department of Health and Human Services [http://thetaskforceblog.org/2013/07/22/hhs-secretary-sebelius-announces-new-lgbt-data-collection/](http://thetaskforceblog.org/2013/07/22/hhs-secretary-sebelius-announces-new-lgbt-data-collection/) and non-profit research organizations such as the Williams Institute.

**ENGAGEMENT**

Getting to the table is half the equation. Ensuring that participants are best able to fully engage in the process and that their input is meaningfully received and heard is equally as important. Many of the populations DEC and its member organizations represent experience other challenges in accessing spaces where policy decisions are made and their perspectives are often misheard or misunderstood.
Making the White House Conference on Aging and its related events maximally accessible for the broadest range of participants is a critical way to ensure the best feedback from the most diverse range of perspectives. Some steps to move in that direction include:

**Language**- The communities that the DEC and its members serve include populations with the highest percentages of limited English proficiency (LEP). Adherence to policies such as the standards set in place by Executive Order 13166 around language access are a start.

**Cultural Competence**- All too often, the larger concept of cultural competence is only operationalized in the most basic ways, such as meeting needs of LEP individuals. Cultural competence requires more fundamental response to the particular needs and circumstances communities face. For example, transgender elders interested in participating may require events to mark and discuss gender in different ways. Guides such as the National Standards for Culturally and Linguistically Appropriate Services in Health Care and SAGE’s training on cultural competence in the LGBT community will be helpful here.

**Technology**- Technology has been offered as a means to improve accessibility for events and as a way to maximize engagement. Unfortunately for too many of our communities, over-reliance on technology exacerbates the disparities communities have in accessing technology across the digital divide. The Pew Research Internet Project reports that African American and Hispanic populations trail their white counterparts in internet use. Language access is a strong indicator of internet use as well, so LEP communities are disproportionately likely to have limited access to technology. Coupling technology with other linguistic and culturally competent practices will help minimize the digital divide for events and activities.

**CONCLUSION**

“Inclusion” and “Engagement” are not destinations that one can reach by enacting any set of principles- they are values that require intentionality and at the same time, they are goals that can be moved towards in measurable ways through strategic use of resources. The DEC and its member groups know the difficulty in moving towards inclusiveness and fuller engagement and appreciate the steps taken thus far. We stand ready as partners in providing support and resources in providing expertise as the White House Conference on Aging seeks to bring together elders that better reflect America and all its diverse perspectives.
May 29, 2015

Nora Super
Executive Director
White House Conference on Aging
200 Independence Avenue SW, Suite 637D
Hubert Humphrey Building
Washington, DC 20201

Dear Ms. Super:

The Diverse Elders Coalition would like to take this opportunity to respond to the four Policy Briefs released by the 2015 White House Conference on Aging (WHCOA). The WHCOA is a once-in-a-decade opportunity to not only focus the nation’s attention on the needs of our elders but to also reflect on and respond to the changes in our communities and in our nation since the last conference.

The United States has changed dramatically since the last WHCOA convened in 2005. Demographically, the nation is not only moving to what has been referred to as the “Graying of America” as Baby Boomers hit retirement age, but also the “Browning of America” with an increasingly multi-racial, multi-ethnic population. Discussions around racial justice and its impact on our seniors are increasingly important to have, not just at the dinner table, but at the policymaking table. These changes have come hand-in-hand with the emergence of the LGBT community as a constituency whose needs in the policy arena are transforming conversations around gender, marriage, and the very nature of who is considered an “underrepresented minority.” Finally, the challenges faced by both indigenous communities and immigrants with varying degrees of citizenship status have brought forward more fundamental questions about who even gets to be considered “an American.”

These new circumstances and new realities, both political and demographic, require new kinds of policy discussions, and we commend the WHCOA team for attempting to grapple with them as you prepare for this important conference. We appreciate that the WHCOA website talks about “broad public engagement” and “accessibility to the widest possible audience,” we also applaud your commitments to our diverse constituencies through meetings, events, and correspondence. Through specific events intentionally targeting diverse constituencies, such as the May 6th listening session with tribal elders and the May 7th Los Angeles Town Hall, you have demonstrated commitment to proactively incorporate our communities’ voices into your work.

We recognize and appreciate your commitment, but we need more support. And our communities need more support. The elders our member organizations serve continue to be among the most marginalized. Ageism, racism, xenophobia, homophobia, and transphobia create additional layers to the considerable challenges our communities face as they age. These challenges require our full commitment and creative partnership to engage our communities and make sure they’re part of your important work to find policy solutions.

We have identified three major themes that we would like to address in response to the WHCOA policy briefs on Healthy Aging, Elder Justice, Retirement Security, and...
Long Term Services and Supports, which include:

1) Data/Research;
2) Cultural and Linguistic Competence; and
3) Non-Discrimination and Equal Treatment Under Law

These themes represent opportunities for the WHCOA to address specific issues in your outreach, policy analysis, and conference planning, and we look forward to serving as thought partners and resources to you in that important work.

Below, we provide some initial observations about each theme and recommendations for future work. Specific recommendations appear in bold.

**Data/Research**
The historical marginalization and intentional erasure of our constituencies’ lives and experiences, coupled by pragmatic realities of small sample size and data collection challenges, has resulted in a “cycle of mutual neglect,” where policymakers do not (or will not) identify the needs of our communities, and our communities get the message (intended or not) that their needs do not matter. In turn, our communities, thinking their needs do not matter, do not (or will not) engage policymakers, and policymakers take silence to mean consent with the status quo. Even when there is data about our communities, at times, that data is only collected and reported on in the aggregate, masking real and serious disparities specific communities face.

Despite the WHCOA’s best intentions, there remains much work to do in gathering the best knowledge about our communities. For every instance where our member organizations have partnered with our constituencies to engage the WHCOA’s work, there are an equal number of instances where we remain invisible. The Policy Briefs themselves only make uneven references to communities of color and American Indian/Alaska Natives. On LGBT elders and their needs, the Policy Briefs are resoundingly silent.

Our member groups recognize the challenges of data collection and data disaggregation for our communities. On many occasions, the lessons our groups have learned in strategic over-sampling and community-based research methodology represent the best available current thinking about how to understand our communities’ needs. The WHCOA represents an important opportunity to bring together that best thinking and be a central repository for the best research about diverse elders, and we call on you to gather best practices in terms of data collection and disaggregation and to employ them in the research you do to inform the policies that are put forward.

**Cultural and Linguistic Competence**
Many of the recommendations put forth in the Policy Briefs talk about inclusion and intend to be applicable to all elders, but we know that one solution does not fit all. It is often our constituencies whose needs are least addressed in such cookie-cutter approaches; thus, our member organizations have spent decades promoting more culturally competent responses to addressing our elders’ needs. Making sure that elders who are English language learners (ELL) have services that are in the languages they speak is just one way to move towards cultural and linguistic competence. Recognizing that “culture” is not only defined through traditional lenses of race, ethnicity, or nationality, but also by other ways that people identify such as gender, gender identity, or sexual orientation, is a key component to building culturally competent services and
programs. Again, our member organizations have built track records of success in articulating and implementing such practices and their example would be of great help to your work. We strongly urge the WHCOA to identify the best practices in terms of providing culturally and linguistically appropriate services and programming to ALL elders and to commit to implementing them across the board.

**Non-Discrimination and Equal Treatment Under the Law**

Despite advances that our communities have achieved on the road to equality, there remain considerable barriers to their full participation in every facet of public life. It is often difficult enough to move through the world as a person of color, or an LGBT person; the additional barriers that age places on the individual complicates the picture even further. The Policy Briefs and the analyses they put forth do not sufficiently recognize this complexity and remain silent on the unique needs of elders who face multiple forms of discrimination. The safety net of federal programs and benefits that are intended to support everyone in their old age are unevenly distributed on the basis of citizenship; they are often unavailable not only for non–citizens and undocumented immigrants, but also for American Indians/Alaska Natives and other indigenous communities with varying degrees of citizenship. LGBT elders, despite the rapid pace of progress being made on issues like marriage equality, still are not afforded federal protections against discrimination. Communities of color continue to experience de facto, if not de jure discrimination and have unequal outcomes as a result. **The policies that are intended to benefit all elders must be as inclusive as possible and contain the strongest language available around non-discrimination and equal treatment.**

These overarching themes offer a framework for the WHCOA to improve its work to address the needs of ALL elders. The Diverse Elders Coalition and its member organizations stand ready to partner with you to meet those needs and to fully realize the conference’s goal to “ensure that Americans throughout the lifespan have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in community life.”

If you require further information, please do not hesitate to contact me on behalf of the coalition by e-mail at bdeguzman@diverseelders.org or by phone at 202-347-9733. Thank you for your support and we look forward to your continued partnership.

Sincerely,

Ben de Guzman

cc: Michael Adams, SAGE
    Randella Bluehouse, NICOA
    Dr. Yanira Cruz, NHCOA
    Quyen Dinh, SEARAC
    Dr. Wesley Lum, NAPCA
Dear Ms. Super:

In consultation with you and your staff at the White House Conference on Aging, as well as with our member organizations, we at the Diverse Elders Coalition would like to submit this addendum to our previous response to the four Policy Briefs your office has released. The recommendations below reflect more specific policy language that our member organizations have put forth in their advocacy work. In terms of federal agencies for specific review or analysis, while some of the recommendations we put forth seek broad based application across the entire government, we also identify some specific agencies where some of these recommendations have more specific provenance.

As in our previous response, we have provided our recommendations in three areas: Data/ Research, Cultural Competence, and Non-Discrimination and Equal Treatment Under the Law:

**Data/Research**

Data collection for diverse elders faces many challenges, including: small sample sizes of specific populations, emerging methodologies that are still identifying the best ways to survey respondents on sexual orientation and gender identity, and hard to reach populations due to factors such as: limited English proficiency, immigration status, and fear of homophobia/ transphobia. Building off our previously submitted response to the WHCOA Policy Briefs, we provide additional recommendations below:

SEARAC has supported data collection that, provides enhanced and segmented data that, at the minimum, includes disaggregated race categories used in the Decennial Census—which includes a broader range of different Asian American and Pacific Islander racial groups. Further, SEARAC supports the inclusion of cross-tabulated data by gender, disability, and English proficiency.

SAGE’s policy recommendations call for prioritizing the collection of data related to sexual orientation and gender identity in its population based surveys, including those from the U.S. Census Bureau, such as the American Community Survey, the National Decennial Census, and the Current Population Survey.

Having research that captures disaggregated data on racial groups and improved data on sexual orientation and gender identity across the age spectrum will help provide a better picture of the needs, challenges, and resiliences that exist among elders of color and LGBT elders. Applying these standards across all federal agencies that serve elder populations and requiring all agencies that receive federal funding to meet these standards will also be helpful.
Cultural and Linguistic Competence

The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards) provide a baseline of practices and policies that can be used to measure cultural competence. It is not clear to us that all programs across the board that serve elders and receive federal funding to do so have minimum standards for cultural competence and it will be important for any policy coming out of the White House Conference on Aging to make a clear statement about not only the need to have culturally and linguistically competent services for elder populations, but to have clear standards and metrics to measure progress towards that goal.

SAGE’s work has made it very clear that LGBT constituencies have specific needs and that commonalities around sexual orientation, gender, and gender identity constitute communities that have their own cultural contours and require culturally specific policies as well. Their policy asks identify specific agencies where cultural competence standards and practices would be helpful, including State Units on Aging (SUAs) and Area Agencies on Aging (AAAAs), as well as HUD and programs that provide housing for LGBT people.

Non-Discrimination

An Executive Order barring discrimination on the basis of sexual orientation and gender identity in entities that serve older adults with federal funds is one of the key policy recommendations put forth by SAGE. This would apply across all agencies and be applicable to any federally funded institution, including nursing homes and long term care settings. Citizenship becomes another aspect around which elders of color and/or LGBT elders face discrimination in aging settings. Federal immigrant eligibility restrictions in Medicaid, for example, require a five year waiting period for lawfully residing immigrants. Undocumented immigrants are not allowed to purchase private plans in the health insurance exchanges and continue to be eligible for most other public programs. Policies and programs serving elders are available unevenly across Indian country and are not uniformly available for Native Hawaiian and Pacific Islander elders that reside in territories or elsewhere besides the fifty states.

Religious discrimination in settings that are funded by the federal government affect diverse elders in a variety of ways. Elders who are Muslim or Sikh for example, are not sufficiently protected by racial profiling language that still contains exemptions for national security. At the same time, current laws and policies are being mis-interpreted or re-enacted to allow for discrimination against LGBT people justified by “religious freedom.” Agencies and programs that serve elders should be held to standard non-discrimination language that maintains religious freedom for sincerely held belief and at the same time protects vulnerable populations from being discriminated against.

We hope that this additional guidance will help you make more informed policy recommendations and we look forward to working with you up to the July 13th White House Conference on Aging, and more importantly, beyond that one-time event to develop long-standing policy change that makes concrete improvements in the lives of the diverse elder constituencies our members represent, and indeed, for all elders in the United States. As indicated before, please contact me via e-mail at bdeguzman@diverseelders.org or by phone at 202-347-9733 if you require anything further.

Sincerely,

Ben de Guzman

cc: Michael Adams, SAGE
    Randella Bluehouse, NICOA
    Dr. Yanira Cruz, NHCOA
    Quyen Dinh, SEARAC
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The Diverse Elders Coalition (DEC) advocates 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—racially and ethnically diverse older adults; LGBT older adults; and poor and low-income older adults. 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. We envision a world where all older adults can live full and active lives as they age.