

NHCOA

NATIONAL HISPANIC COUNCIL ON AGING

Working to improve the lives of Hispanic older adults, their families and caregivers!



Status of Hispanic Older Adults: Insights from the Field – Reframing Aging

WASHINGTON D.C.

2018

2201 12th St NW, Suite 101, Washington, DC 20009 | 202.347.9733 | nhcoa@nhcoa.org

Reframing Aging /rē' frām 'ājiNG/

Many Americans think of aging as deterioration, decline, and dependency. If we reframe how we talk about aging, over time we can change how we think about aging. Aging is a process of “building momentum”. When discussing aging, we need to focus on experience and wisdom which enable older adults to improve their communities. By framing aging as a dynamic and forward-moving process we can help people see aging in a more positive light.¹

National Hispanic Council on Aging
2201 12th St NW, Suite 101
Washington, DC 20009
www.nhcoa.org

Note: Throughout this report, we use the terms Hispanic and Latino interchangeably.

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Every year, NHCOA distributes a national survey, and this year's survey focused on Reframing Aging. We also reissued our caregiving survey as we continue to work on family caregiving. NHCOA would like to thank the community-based organizations and their dedicated staff members for their participation in implementing these national surveys. We appreciate the time and energy put into making the data collection process a success. In addition, we want to express our gratitude to all the older adults, family members and caregivers who participated in the survey.

A special thanks is extended to the Town Hall and Empowerment and Civic Engagement Training participants in Miami, Florida; Silver Spring, Maryland and Los Angeles, California. These participants included older adults, caregivers and service providers who gave their time, shared their personal stories and perceptions, and provided recommendations. We also want to thank the participants of our Thought Leaders Roundtables.

We would like to recognize the NHCOA staff members who contributed their time and effort to the development of this report. Christine Pérez and Christina M. Pacheco were instrumental in developing the National Reframing Aging Survey and the National Caregiving Survey and collecting and analyzing the data. Nicolas Peña, Fatima Velez, Christine Perez, Margarita Navas and Andrea Montes played major roles in organizing the Regional Conferences, facilitating the Empowerment and Civic Engagement Trainings and organizing the Thought Leaders Roundtables. Christine Perez and Christina Pacheco conducted the literature review and Christina M. Pacheco and Christine Perez drafted the report, while the entire NHCOA team participated in editing the report. The implementation of the study and production of the report was directed by President and CEO, Dr. Yanira Cruz.

Finally, we would like to express our deepest gratitude to our sponsors, who, with their generous contributions, allowed us to host our Regional Conferences in Miami, Florida, Silver Spring, Maryland and Los Angeles, California and our Thought Leaders Roundtables on Reframing Aging. Through these conferences and roundtables, we had the opportunity to listen to Hispanic older adults, their families and caregivers and engage them in discussions that contributed greatly to the recommendations included in the report. These sponsors are AARP, Alzheimer's Association, Matrix, PhRMA, Eli Lilly, Better Medicare Alliance, Independent Living Systems Inc., Montgomery County, The Latino Health Initiative, Herbalife, Archstone Foundation, Univision, Pfizer, The California Endowment, Anthem, Aetna, and The NASH Education Program.

NHCOA Recommendations

Building on the findings presented in this report, NHCOA has developed a number of recommendations for local, state and national leaders. We also advance specific recommendations from Hispanic community members, community- based organizations and grassroots leaders. NHCOA forwards the following recommendations to reframe aging from its current negative connotation to one of empowerment and positivity:

1. Reframe aging as a journey, not a destination, recognizing it is a multigenerational issue.
2. We need to build intergenerational bridges to play a major role in Reframing Aging. It is very important to include the support of millennials, as we move forward.
3. The power of the media and access to diverse communities are important ways to positively influence the conversation about ageism.
4. We must include positive aging and age inclusive principles in relevant academic forums, e.g., Schools of Public Health and social work.
5. We must prevent discrimination, age exploitation and disability exploitation by working against guardianship abuses through solid messaging campaigns and legal aid partnerships.
6. Use of equal opportunities, shared responsibilities, equal participation and appeal to a shared value of justice.
7. Bipartisan passage of H.R.947 and S.337, the Family and Medical Insurance Leave Act (the FAMILY Act).
8. Invest more funding in training initiatives to support and train family caregivers in their roles as caregivers.
9. Pass local level regulations to financially support family caregivers who are aiding older adults age in place.
10. Partner with Latino organizations to develop programs and services that meet the specific needs of Hispanic older adults, catering to the strengths of communities, and build trusting relationships.

Table of Contents

Acknowledgments. 2

NHCOA Recommendations. 3

Executive Summary. 5

Literature Review. 6

Reframing Aging Thought Leaders Roundtables. 10

National Reframing Aging Survey. 12

NHCOA Regional Conferences. 17

National Caregiving Survey. 20

Policy Report. 24

Sources Cited. 26

Executive Summary

Hispanics are a remarkably resilient population. Hispanic older adults continue to face daunting challenges in the areas of discrimination and ageism, healthy aging, retirement security, housing and access to programs. This year we focus on reframing aging as discrimination and ageism touch all spectrums of aging and inhibit older adults' abilities to age with dignity. Older adults remain eager to work, be civically engaged, share their wisdom, experiences and insightful and concrete recommendations to address the challenges they face.

This year our focus on reframing aging was illustrated as NHCOA implemented a National Reframing Aging Survey, a series of Reframing Aging Thought Leaders Roundtables and a series of Regional Conferences. The Hispanic older adults and caregivers that participated in these events were enthusiastic about working to change the narrative about aging. In addition to our work on reframing aging, we also continued to focus on caregiving and included a focus on precision medicine as we partnered with the National Institutes of Health's All of Us Research Program.

The challenge of reframing aging may seem daunting, but the dedication of community leaders, aging focused nonprofit organizations, decision makers and experts working together, can find solutions on how to address the challenges faced by Hispanic older adults, their families, and caregivers. The 2018 Status of Hispanic Older Adults: Insights from the Field - Reframing Aging Report documents the information gathered this year about the challenges faced by Hispanic older adults and recommendations on how to overcome those challenges while redefining aging.

The first approach was the implementation of a literature review to compile the existing data on the state of Hispanic older adults. The second approach was the implementation of a series of Thought Leaders Roundtables and Regional Conferences designed specifically to elicit solutions to the pressing problems faced by Hispanics. The third approach was a national survey conducted by NHCOA to understand how people view aging and ways in which we can reframe the concept. We present summary results of each of these approaches to gain better insights into reframing aging in 2018.



Literature Review

The literature review compiled data about reframing aging as well as issues that came up at the regional conferences in 2018. Highlights from the literature review are summarized, by topic, below:

Reframing Aging

- Most older adults remain in the workforce well after reaching the age of 65. Older adults are eager to contribute to their families and their communities. Given these reasons, we need to reframe the views and perceptions our society has about older adults and develop a more inclusive framework. Therefore, we must begin to reflect on our attitudes, perception, and words with regards to aging.
- Negative perceptions about aging include the idea that aging is synonymous with deterioration, dependence and/or incompetence. These false perceptions of aging are often supported by the media, entertainment, beauty industries, as well as the public.
- The report, *An Empirical Approach to Reframing Aging and Ageism*, issued by the FrameWorks Institute, indicates that experts in the field of aging have a different view of ageism than the public.²
 - Experts from the field of aging view aging as an opportunity for growth, contribution, and view older adults as independent and healthy.²
 - The public views aging in a negative light, associating aging with decline, disease or disability.²
 - These views result in stereotypes and can lead to discrimination against older adults.²
- The word “aging” and the misunderstandings that go hand in hand with it can be a barrier to better practices and policies for older adults.

Older Adult Latinos



- The Latino population in the United States of America (US) is increasing in size, visibility, and diversity. Projections are that Latinos aged 65 and older will increase from the current 8% of the US population to 22% by 2060.³
- Data support that aging Latinos are more likely to have limited formal education, lower income, and poorer health outcomes than the general population.³
- Historically, Latino populations have been concentrated in California, Texas, Florida, and New York [6]. Latino resettlement across the US has generated new-growth communities especially in the Southeast, Midwest, and Northeast.³
- Major concerns for Hispanic populations include the unresolved legal status of undocumented immigrants, continued low levels of insurance coverage even after healthcare reform,

unfavorable trends in health behaviors, and continued disadvantages in educational attainment and income relative to whites.⁴

- Among states, California had the largest Hispanic total population (15.3 million) in 2016, while Texas had the largest numeric increase in the Hispanic population (233,100). New Mexico had the highest Hispanic share of its total population at 48.5 percent.⁵
- Fifty percent or less of Hispanic older adults are proficient in English. Some 55% of Gen Xers and 52% of Boomer Hispanics speak only English at home or speak English very well.⁶
- Among the oldest Hispanics, just 43% are proficient English speakers and 22% do not speak English at all.⁶

Latino Millennials

- Hispanics are the youngest major racial or ethnic group in the United States.⁶
- There are 24 million Hispanic millennials in the United States; accounting for almost half of the total U.S. Hispanic population.⁷
- Hispanic millennials are a digital-savvy group, increasingly embracing mobile and social media platforms.⁷
- Fifty-three percent of Hispanics in the United States are parents and value spending time with their families over everything.⁷
- Millennials are currently much more likely to be US born and are more likely to speak English proficiently.⁶
- Nearly 66% of Hispanic millennials are of Mexican origin, 16% are of Caribbean Hispanic origin: including 9% who are Puerto Rican. One-in-ten are of Central American origin, including 4% who are Salvadoran, and 6% are of South American origin, including 2% who are Colombian.⁶
- About three-quarters of Hispanic millennials are proficient in English. About 19% of Hispanic millennials speak English less than very well and 5% do not speak English at all. However, 72% of Hispanic Millennials speak Spanish at home.⁶
- 65 percent of Millennial Latinos, ages 18-29, say they have “experienced discrimination or unfair treatment because of their race or ethnicity.” However, only 35 percent of Latinos, ages 50 and older, report the same thing.⁸
 - This may be explained by the empowerment of Latino Millennials who see an infringement on their equality status as something not tolerated.⁸



Caregiving



- Providing assistance for older generations is a source of great cultural pride within Hispanic communities, yet almost half (44%) of these caregivers reported feeling stressed and even overwhelmed by the caregiving responsibility.⁹
- What motivates Hispanics to become caregivers to their older adults is *familiarismo*, their cultural values that are passed on from generation to generation.
- Latino family caregivers in the U.S. spend more of their time and money caring for a loved one compared to the rest of the population. On average, Latino family caregivers spend 44% of their annual income on caregiving-related expenses and 52% more time per week giving care.¹⁰
- Latinos make up 21% of the estimated 40 million family caregivers in the U.S. who provide unpaid care to their family and other adult loved ones. Many family caregivers, especially men, see themselves as just family members doing what loved ones do for each other. Often they are unprepared to handle the more complex aspects of the role.¹⁰
- Long-distance caregivers who live more than one hour from the person they provide care for, incur the highest out-of-pocket costs annually (\$11,923).
 - Caregivers living with their care recipient also incurred \$8,616 annually.¹⁰
- The average Hispanic caregiver:
 - Is a 42.7-year-old female,
 - Provided care in the last 12 months, typically to a 65.3 year old female relative, and
 - Provides care without the assistance of paid help.¹¹

Millennial Caregivers

- The majority of U.S. Hispanic millennials (73%) serve as caregivers, in some capacity, to their aging parents, grandparents and other family members.⁹
- Millennial family caregivers on average provide more than 20 hours per week in care.¹²
- Roughly three in four millennial family caregivers are employed. One in three employed millennial family caregivers earn less than \$30,000 per year.¹²



Health

- Four factors that aid in delivery of services to Latinos were (1) language competence, (2) cultural knowledge in multiple contexts, (3) empathy toward clients, and (4) the will to act.³
- According to one study, chronic diseases, particularly diabetes, heart disease and hypertension, were reported as the top health concerns by older adult Latinos.³

- Mental health issues including dementia, Alzheimer’s disease, depression, stress, and insomnia are reported as top mental health concerns among Latino older adults.³
- Over 26% of Hispanic older adults lack health insurance, compared to 10.5% of non-Hispanics, making it difficult for Hispanics to access quality healthcare.¹³

Alzheimer’s disease and Other Dementias

- Older adult Hispanics and Blacks are more likely, on a per-capita basis, than whites to develop Alzheimer’s or other dementias.¹⁴
- This is due to several factors including:
 - High rates of chronic disease (hypertension, diabetes and heart disease) known risk factors for Alzheimer’s and other dementias, and
 - Longer life expectancy of Latinos, which is the greatest known risk factor for Alzheimer’s.¹³
- The number of diagnosed cases of Alzheimer’s among Latinos is only expected to rise, reaching an estimated 1.3 million Latino older adults by 2050.¹³

Precision Medicine

- The All of Us Research Program is based on precision medicine, and takes into account a person’s lifestyle, environment, and family medical history.¹⁵
- All of Us—which is being led by the NIH, aims to create the largest health database ever, by enrolling one million or more people across America.¹⁵



Clinical Trials

- Latinos make up less than 1% of participants in NIH-funded research, and only 6-7% of all clinical trial participants.¹⁵
 - This is problematic, as there are real differences in how people of diverse backgrounds respond to different diseases and treatments.¹⁵
- Underrepresentation in clinical trials means Hispanics have less access to experimental cutting-edge treatments and researchers have less data on how a drug works in that population.¹⁶

NHCOA Reframing Aging Thought Leaders Round Tables

NHCOA's 2018 edition of the Thought Leaders Round Tables focus on Reframing Aging in collaboration with the leaders of other national aging organizations (AARP, The American Society on Aging, Grantmakers in Aging, the Gerontological Society of America, the American Federation for Aging Research, the American Geriatric Society, the National Council on Aging, and NHCOA).



These roundtables have been, and continue to be, hosted nationwide in major cities, including: Washington, DC, Albuquerque, NM, New York, NY,. These roundtables are designed to engage individuals representing key sectors such as aging, caregiving, public health, public policy, government, media, community-based and national organizations, and the faith community to eradicate the misconception that older adults are incompetent, dependent, and most importantly a deteriorating population.

During the facilitated discussions, attendees developed practical solutions to address ageism and reframe aging as a positive process of life. The information gathered from these dialogues will be used to create awareness about ageism and reframe aging in the Hispanic community and other diverse populations.

Terminology Recommendations:

- Adult people
- Older adult
- We, Us
- Influencer (values wisdom)
- Experienced
- Wise
- Wisdom

Reframing Aging Roundtable Recommendations:

1. Educate influencers about ageism and how to reframe aging.
2. Prioritize human connections in policy to spread knowledge and education using intergenerational approaches.
3. Include youth in messaging about aging to change the image of “aging”.
4. Work with media and entertainment industry to tell stories that include all and resonate for all.
5. Prevent discrimination, age and disability exploitation by working against guardianship abuses through solid messaging campaigns and legal aid partnerships.
6. Coordinate efforts across public, private and government sectors to effect larger change.

7. Create programs to allow older adults to age in place.
8. Focus on the positive aspects of aging, not just the negatives.
9. Activism and policy campaigns, e.g., Paid Leave campaigns, play a huge role in building intergenerational bridges. Activism is strength based, showcase older adults' contributions, voice and leadership.
10. Change vocabulary that is inherently ageist like "getting old".
11. Highlight that aging is a process that begins at birth, it is a journey, not a destination.
12. Use of equal opportunities, shared responsibilities, equal participation and appeal to a shared value of justice.
13. Consider cultural stigmas that exist. Highlight our power to support one another, balanced with addressing the everyday needs of older adults, the challenges they face and the joys and triumphs of aging.

We recognize ageism is a problem and these roundtables allow us to generate practical solutions to address ageism and reframe aging. The results help us build a library of positively slanted terminology for aging and older adults in Spanish and in English. This work allows us to continue the reframing aging momentum at the local and national level.



National Reframing Aging Survey

In 2018, NHCOA administered its first National Reframing Aging Survey. It was administered in Spanish and English and could be taken online or in-person. For this survey, we targeted everyone, to ensure we had a broad understanding of aging in the United States. Survey participation was voluntary and anonymous.

The goal of the National Reframing Aging survey was to:

- Understand how Latinos view aging,
- Describe the truths and challenges of aging, and
- Highlight community driven ways to reframe aging.

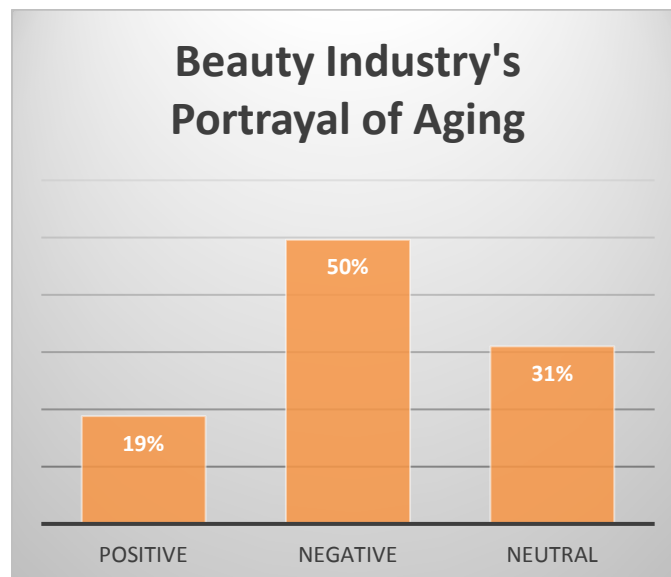
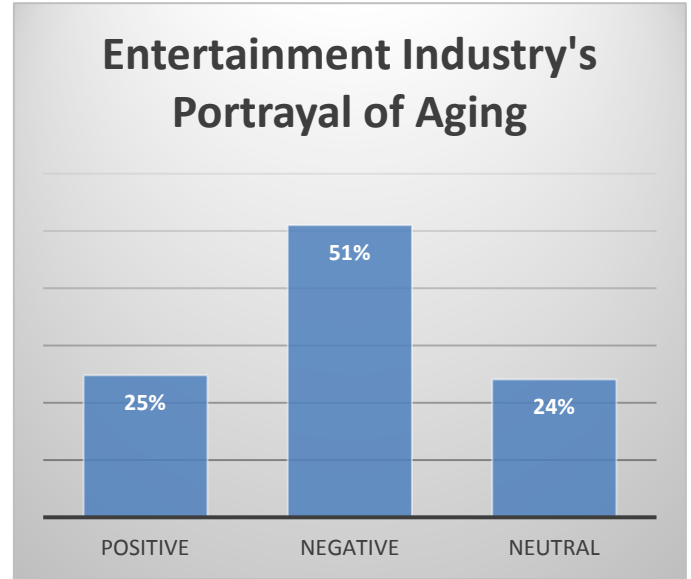
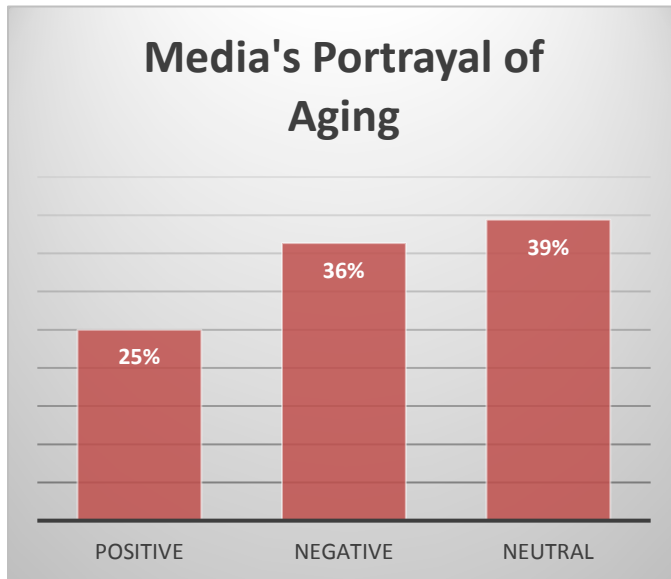
Between March 2018 to August 2018, NHCOA surveyed 136 Latinos. Thirty-nine percent (39%) of participants took the survey in Spanish and sixty-one percent (61%) took the survey in English. A quarter of survey participants (25%) were between the ages of 55 to 64 years. Thirty percent (30%) of survey participants were over the age of 64. Twelve percent (12%) of participants were between the ages of 18 years old and 34 years old. Thirty-three percent were between the ages of 35 and 54.



Many of the questions were open-ended free-text response questions. To analyze these questions, the team coded/organized the text data them and developed themes. As a visual representation of text data, we then used word clouds to show the saliency of themes.

Portrayal of Aging by Industries

We asked survey participants to comment on the nature of the portrayal of aging by different industries, specifically, the media, entertainment and beauty industries. Below we show that overwhelmingly, survey participants felt that the portrayal of aging by the media was neutral or negative. Survey participants overwhelmingly felt that both the entertainment and beauty industry negatively portrayed aging.



NHCOA Regional Conferences: Building Bridges to Engage Diverse Communities

NHCOA implemented three regional conferences in 2018. These conferences were held in Miami, Florida; Silver Spring, Maryland; and Los Angeles, California—cities which together broadly span the diversity of the Hispanic population, in terms of time in the U.S. and countries of origin. The focus of these regional conferences is to provide a linguistically and culturally safe space for attendees to discuss community driven solutions to important issues facing Hispanic communities with special emphasis on engaging diverse communities to achieve mutual goals in the areas of health, economic security, housing and empowerment and leadership. The goals of these conferences are to gather information about engaging diverse communities around shared goals and how to effectively support communities while advocating for local and national level policies that mutually benefit all communities. These conferences featured panel discussions on key issues faced by diverse communities which opened the floor to group discussions and possible solutions.



Miami, Florida

The key issues addressed by Miami, FL community members are:

- Civic Engagement
- Economic Security
- Caregiving & the RAISE Family Caregivers Act
- Health Issues
 - Precision Medicine (All of Us Research Program)
 - Alzheimer's disease
 - Parkinson's disease
- LGBT Anti-discrimination laws
- Nonalcoholic Fatty Liver Disease (NASH)

Silver Spring, Maryland

The key issues addressed by Silver Spring, MD community members are:

- Civic Engagement
- RAISE Family Caregivers Act,
- Paid Sick Leave Law,
- Montgomery County, MD resources for aging,
- Caregiving support,
- End-of-life care,
- Precision Medicine (All of Us Research Program), and
- Participation in clinical trials for Alzheimer's

Los Angeles, California

The key issues addressed by Los Angeles, CA community members are:

- Caregiver support & the RAISE Family Caregivers Act
- Civic Engagement,
- Paid Sick Leave,
- HIV Prevention,
- LGBT Anti-discrimination laws
- Adult Vaccinations, and
- Precision Medicine (All of Us Research Program)

Empowerment & Civic Engagement Training (ECET)

Developing leadership and fostering civic engagement in the Hispanic community is one of NHCOA’s most important activities. NHCOA’s Empowerment and Civic Engagement Training (ECET) helps Hispanic older adults, their families, caregivers, and grassroots leaders become their best advocates when it comes to policies and programs that have an impact on Latino families at the local, state, and federal level.



The Hispanic community cherishes and respects older adults, and the ECET demystifies public policy and advocacy by building on the power and strength of Hispanic older adults’ collective voice. The ECET’s culturally and linguistically competent curriculum is specifically designed to inspire, motivate, and provide participants with the tools and resources to advocate for policies that advance the community in the areas of economic security, health, housing, and leadership development.

The ECET is conducted in Spanish and is targeted to Grassroots Community Leaders who are working and serving the Hispanic community. Over the years, NHCOA has trained hundreds of Latino leaders through the ECET. These leaders are currently leveraging their advocacy skills at different levels and across the spectrum to continue improving the lives of Hispanic older adults.

ECET Learning Objectives:

- What advocacy means
- What each of us brings to the table to be an advocate
- Relationship between power and justice
- How to analyze root causes of a community problem
- How to gather information about that problem
- Identify existing community resources
- How to set a SMART goal to address problem
- How to develop a campaign
- How to use storytelling as a tool for campaign
- How to include stories in a presentation to a decision-maker
- How to create an agenda for a meeting with a decision-maker

ECET Campaigns: The campaigns that ECET participants chose to work on included:

Miami, FL	Silver Spring, MD	Los Angeles, CA
Raising awareness about the RAISE Family Caregivers Act	Raising awareness about the RAISE Family Caregivers Act	
Raising awareness about the NASH Education Program	Advocating for Paid Sick Leave Law	Advocating for Paid Sick Leave Law
Enhancing HIV Education	Enhancing HIV Education	Enhancing HIV Education
Increasing older adult vaccination rates	Increasing older adult vaccination rates	Increasing older adult vaccination rates
Engaging Latino communities in research/precision medicine	Engaging Latino communities in research/precision medicine	Engaging Latino communities in research/precision medicine

ECET Graduates: In 2018, NHCOA graduated a total of 84 new Leaders from its ECET.

Caregiving University: In 2018, NHCOA began developing and piloting its new Caregiving University during its annual ECET by hosting our first Caregiving Webinar Series. The Caregiving University is born out of requests from our constituents to develop linguistically and culturally appropriate trainings that provide family caregivers with the skills they need to be successful in their caregiving roles.



Caregiving Webinar Topics:

Webinar 1: Recursos Clave para los Cuidadores

- Millennials: The Emerging Generation of Family Caregivers
- The Status of the Hispanic Older Adult
- The All of Us Research Program
- Caregiving: a Parkinson's Perspective

Webinar 2: Guía para el buen cuidador Latino

- The RAISE Family Caregivers Act
- The Paid Sick Leave Law
- The *All of Us* Research Program

Webinar 3: Cuidando de un ser querido con Alzheimer's

- Alzheimer's Disease
- Tools and Resources for Caregivers
- Precision Medicine
- Tools for end-of-life care

National Caregiving Survey

In 2018, NHCOA administered the National Caregivers Survey for the second year in a row. It was administered in Spanish and English and could be taken online or in-person at various NHCOA events. Many local community-based organizations and community leaders were instrumental in disseminating this survey to survey takers. The target audience was Latino caregivers. Survey participation was voluntary and anonymous. The goal of the 2018 survey was to:

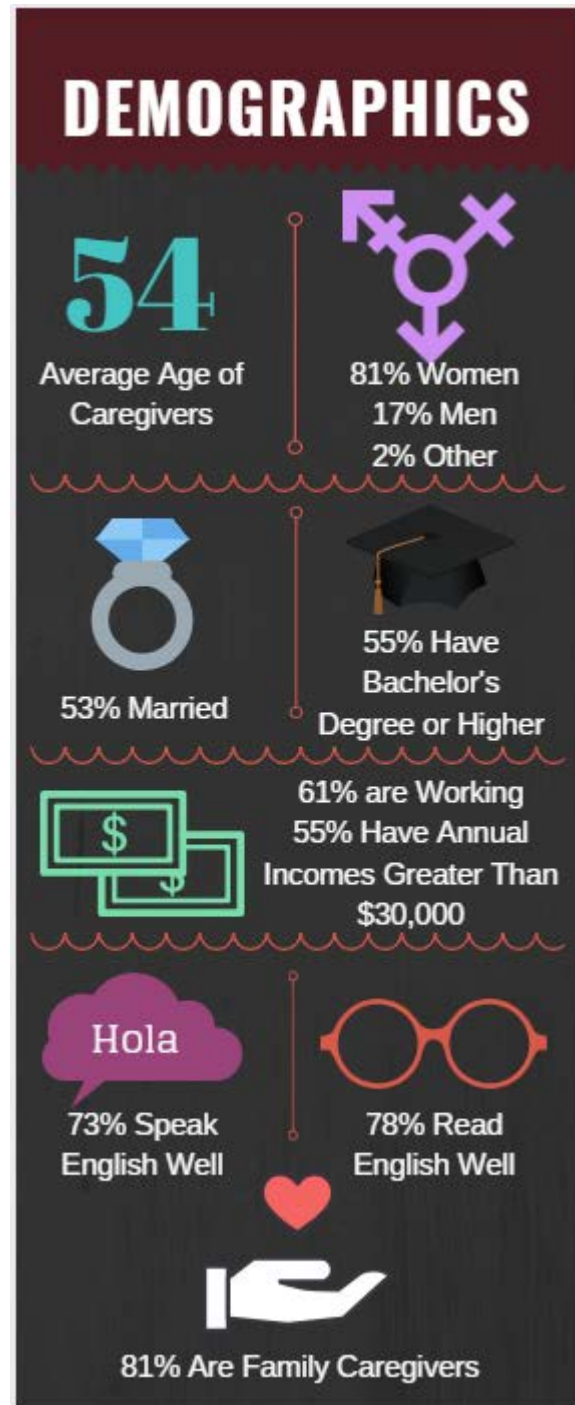
- Further understand the demographics of Latino caregivers,
- Describe the challenges caregivers face, and
- Recognize what resources are needed to aid caregivers in their roles.

Between March 2018 to August 2018, NHCOA surveyed 222 Hispanic caregivers. Fifty four percent (54%) of participants took the survey in Spanish and forty six percent (46%) took the survey in English. Roughly one in five (22%) caregivers were age 65 and older, with an average age of 54 (standard deviation 13.5). The age range of survey takers ranged from 25 years old to 83 years old.

The majority of caregivers were employed (61%) and had incomes greater than \$30,000 (55%). Seventy-eight percent (78%) of Hispanic caregivers provided care for a friend or family member:

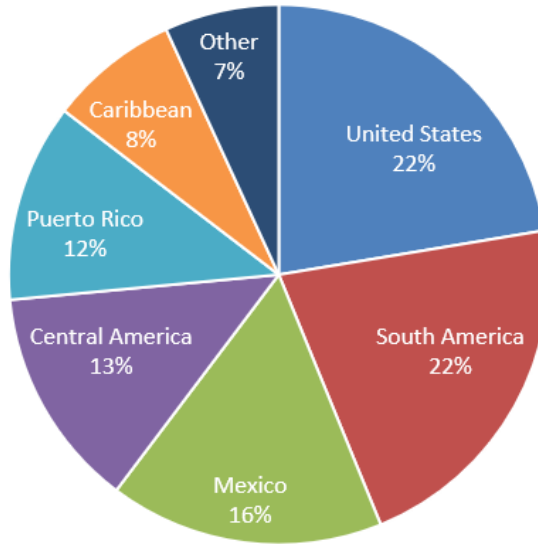
- Parent/Parent-in-law (46%),
- Spouse/Partner (12%),
- Child (13%),
- Friend/Neighbor (7%), and
- Other (36%).*

*Note the percentages do not total 100% as caregivers could select multiple categories.

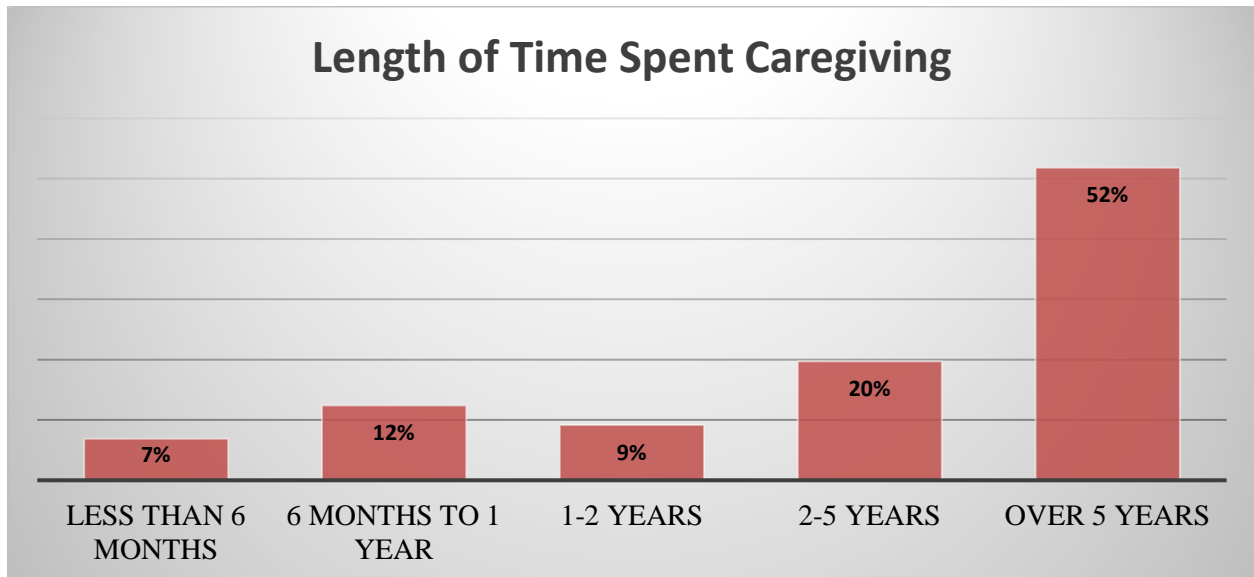


Survey respondents lived in 19 states, Puerto Rico and Washington, D.C. Most respondents live in Maryland (29%), California (21%) and Florida (15%), the sites of this year’s regional conferences. Nineteen countries/territories of origin were represented by caregivers who took the survey, with most having been born in the United States (22%), Mexico (16%), Puerto Rico (12%), El Salvador (9%) and Bolivia (7%).

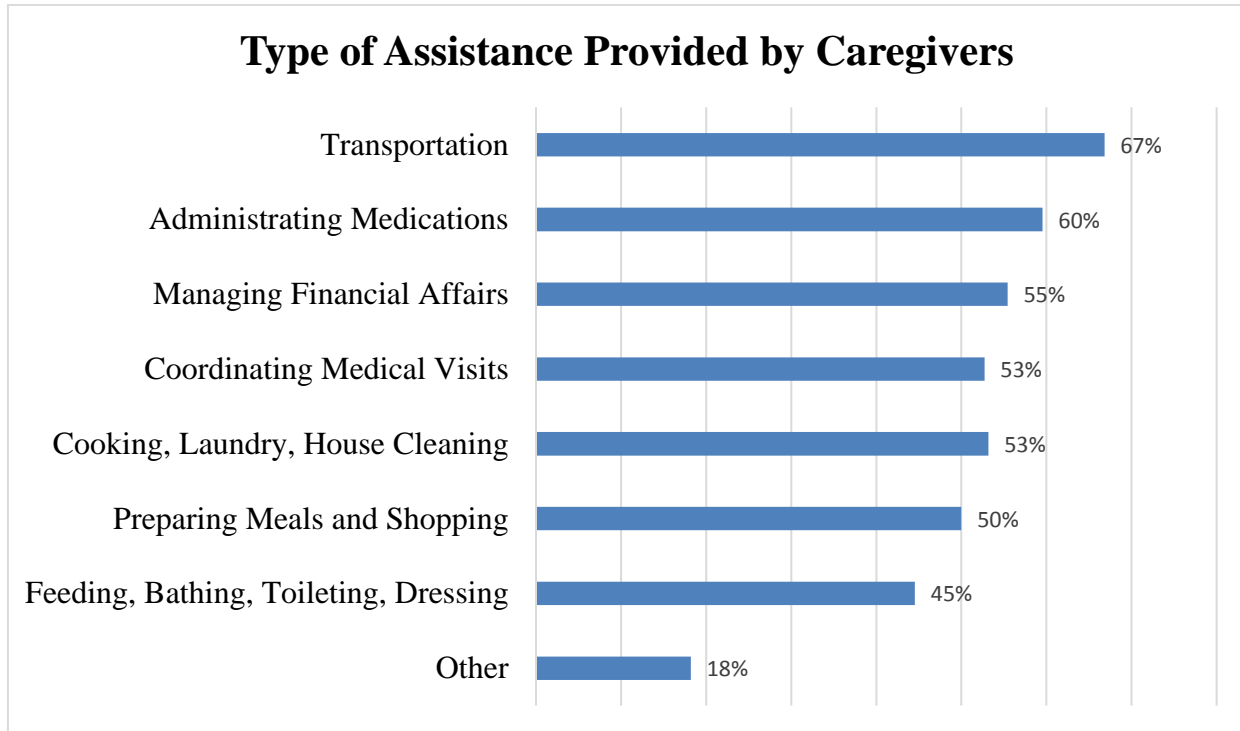
Caregivers' Countries of Origin



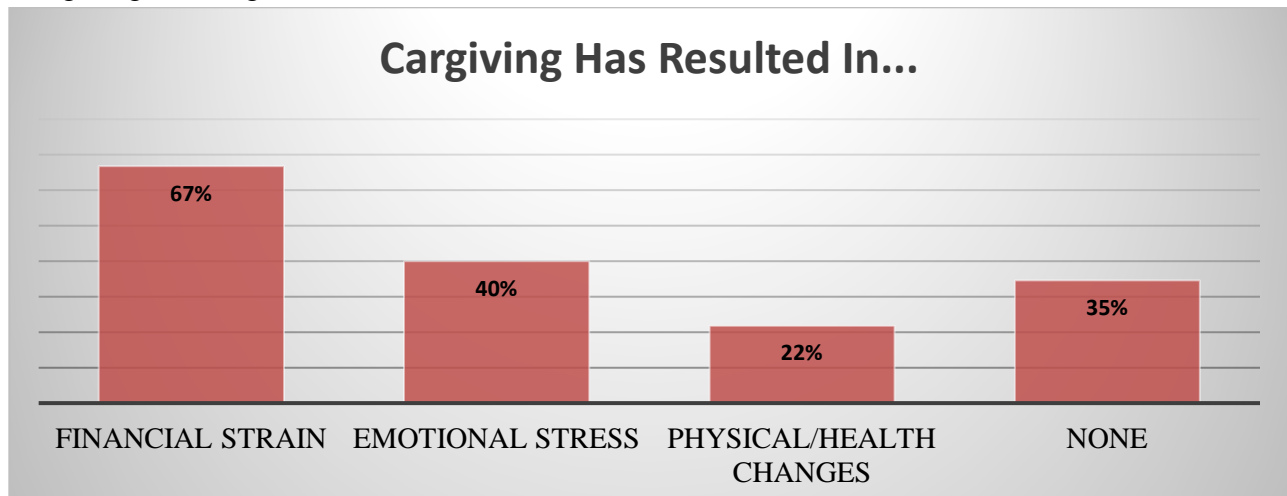
Less than half (47%) of caregivers live with the ones they are caring for and more than half (52%) of caregivers have been providing care for more than 5 years. Additionally, when we asked about the amount of time spent on caregiving, we found that 30% of caregivers spent less than 8 hours a week on caregiving, 25% spent 9-20 hours a week, 13% spent 21-30 hours a week, 12% spent 31-40 hours a week, and 21% spent more than 40 hours a week on caregiving tasks.



Caregivers provide a range of services and assistance for those they are caring for. To better understand the types of assistance that Latino caregivers currently provide to their loved ones, we asked “What kind of assistance do you provide?” Caregivers were able to select multiple services. Most caregivers tended to provide everyday assistance such as transportation administering medications, managing financial affairs, coordinating medical visits, and cooking, doing laundry, and household chores, etc.



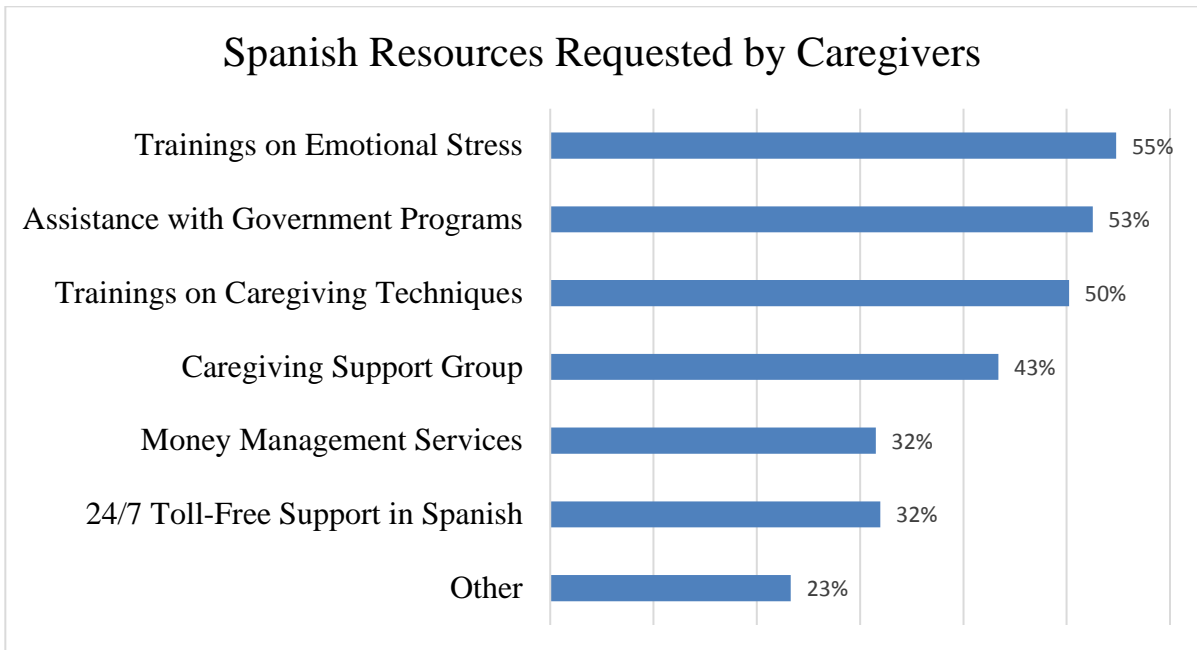
Caregivers provide care to individuals with a variety of conditions including advanced age, dementia, and chronic disease. This experience can be a financial, emotional and physical stressor, and caregivers often experience detrimental psychological, behavioral, financial and physiological effects on their daily lives and health. Latino caregivers overwhelmingly reported (67%) that caregiving is taking a financial toll on them.



Latino caregivers were asked to list their top three challenges they have experienced as a caregiver. Most caregivers (43%) reported that having the money to afford caregiving was among their top three challenges as caregivers. Forty-one percent (41%) of Hispanic caregivers reported not understanding government programs, such as Medicare, Medicaid, SSI, SNAP, etc., was a major challenge. Finally, 39% of Hispanic Caregivers reported balancing family and personal responsibilities was a major challenge. Other challenges included communicating with healthcare providers (33%) and finding information and educational resources (27%).

We also asked caregivers about their changes in employment status due to their caregiving roles and found that slightly more than half (54%) had no change in jobs status. The major change reported was a decrease in hours, however, only 13% reported that change.

NHCOA continues its work on a strategy to support caregivers in their roles. To that end, we asked what Spanish language resources caregivers would like to have. Caregivers were able to choose multiple options and overwhelmingly, caregivers wanted trainings on stress management (55%) and assistance with government programs (53%). Another major concerns among Latino caregivers is that many are untrained, and 50% of caregivers requested trainings on caregiving techniques in Spanish. NHCOA is working to establish a Caregiving University in the coming year.



NHCOA Policy Report

In 2018, NHCOA continues to engage in several policy areas. In 2018, NHCOA has worked on:



Independent Payment Advisory Board (IPAB): The IPAB was established under the Patient Protection and Affordable Care Act (ACA). It was to be a 15-member federal agency that was tasked with achieving savings in Medicare without affecting coverage or quality. The IPAB was granted authority to make changes to Medicare spending. However, Presidents Obama and Trump never nominated a single person to this controversial board. NHCOA, to ensure that Medicare was not limited and that Latino older adults would continue to have access to lifesaving prescriptions, advocated for the repeal of IPAB. Congress voted to repeal the IPAB as a part of the Bipartisan Budget Act of 2018 on February 9, 2018 and President Trump signed that bill on the same day.

Prescription Drug Imports: With rising concerns about medication safety, NHCOA opposed efforts on the Hill to import prescription drugs from other countries.

President’s Proposal on Drug Pricing: In a continued effort to ensure Medicare beneficiaries have access to medications they need, NHCOA co-led a comment letter that was signed by 239 organizations. The letter was in response to a Request for Information (RFI) on the President’s proposal to reduce drug pricing. The letter advocated for health plans to share drug rebates directly with patients and to establish an out-of-pocket spending cap .

Medicare Cliff: The Affordable Care Act included a measure that slowed the growth rate of the “catastrophic threshold.” That measure is set to expire soon. If allowed to expire, it will cause the catastrophic threshold, or the amount of out-of-pocket spending needed to reach catastrophic coverage, to increase by an estimated \$1,250 from 2019 to 2020. NHCOA is advocating for Congress to fix the Medicare Cliff problem.

Family and Medical Insurance Leave Act: H.R.947 and S.337: Paid family leave would benefit all workers, with potentially a greater positive effect on Hispanic workers and their families. Hispanics are a growing segment of the U.S. population and an even faster-growing segment of the workforce. Latino workers are often in low-level jobs that do not offer paid leave benefits. About 44% of Hispanic older adults aged 70 years or more receive informal home caregiving – compared to about 34% of African Americans and 25% of non-Hispanic whites. Considering the growing number of intergenerational households and caregivers across diverse communities, NHCOA recommends a bipartisan passage of the FAMILY Act. Given the growth of intergenerational households and caregivers across diverse communities, NHCOA is working to ensure paid family leave is a priority at the local and national level. NHCOA’s paid family leave initiative mobilizes and informs diverse workers and families of existing state laws that provide paid leave, as well as empower diverse communities in states where these laws don’t exist or have yet to be enacted.

RAISE Family Caregivers Act: In January 2018, President Trump signed the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act into a law. It was a collective triumph! NHCOA continues pushing and supporting the development of a national strategy to support family caregivers.

The RAISE Family Caregivers Act requires the development, maintenance, and updating of an integrated national strategy to recognize and support family caregivers. This law brings together relevant stakeholders on an advisory council to advise and make recommendations regarding the national strategy. The strategy would identify specific actions that can be taken to recognize and support family caregivers.

Caregiver Advise, Record, Enable (Care) Act: This law requires hospitals to 1) Record the name of the family caregiver on the medical record of your loved one, 2) Inform the family caregivers when their loved one is to be discharged, and 3) Provide the family caregiver with education and instruction of the medical tasks s/he will need to perform for the patient at home. The CARE Act has been signed into law in 36 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. NHCOA supports the passage of the CARE Act in all states – as supporting family caregivers is necessary.¹⁷

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National Hispanic Council on Aging (NHCOA)
2201 12th St NW, Suite 101
Washington, DC 20009
Office: 202.347.9733
Email: nhcoa@nhcoa.org
Web: www.nhcoa.org

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