

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



2017 Status of Hispanic Older Adults: Insights from the field – Caregivers Edition

WASHINGTON D.C. 2017

<b>1</b>   P a g e
Family caregiver / fam( $\theta$ )lē 'ker, givər/ $n$ . 1. A relative, partner, friend, or neighbor who has a significant relationship with, and provides a broad range of assistance for, a person with a chronic or other health condition, disability, or functional limitation.
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Every year, NHCOA distributes a national survey, and this year's survey focused on caregiving. NHCOA would like to thank a number of community-based organizations and their dedicated staff members for their participation in implementing the National Caregiving Survey. These organizations include Abriendo Puertas in Miami, Florida, Mexican American Opportunity Foundation in Los Angeles, California, and Montgomery County, Maryland. 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 symposium 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 would like to recognize the NHCOA staff members who contributed their time and effort to the development of this report. Maria Fernanda Mata and Christine Pérez were instrumental in developing the National Caregiving Survey and collecting and analyzing the data. Nicolas Pena, Fatima Velez, Christine Perez, and Andrea Montes played major roles in organizing the Regional Conferences and facilitating the Empowerment and Civic Engagement Trainings that were held in conjunction with the Regional Conferences. Christine Perez 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 deep 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. Through these conferences, 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, DHHS Office of Minority Health, Alzheimer's Association, Verizon, The John A. Hartford Foundation, Matrix, PhRMA, Abbvie, Abbott, Eli Lilly, Better Medicare Alliance, The Social Security Administration, Health Foundation of South Florida, Independent Living Systems Inc., Montgomery County, Herbalife, Archstone Foundation, Univision, Pfizer, The California Endowment, Anthem, and The Henry J. Kaiser Foundation.

#### **NHCOA Recommendations**

uilding 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. In no particular order, NHCOA forwards the following recommendations to better support Hispanic/Latino older adults by ensuring adequate training, support and care for their caregivers:

- 1. Bipartisan passage of H.R.947 and S.337, the Family and Medical Insurance Leave Act (the FAMILY Act).
- 2. Bipartisan passage of S.1028, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act.
- 3. Create a database in which organizations can upload information about services available for caregivers.
- 4. Reframe caregiving as a multigenerational issue.
- 5. Partner with Latino organizations to develop programs and services that meet the specific needs of caregivers, cater to the strengths of communities, and build trusting relationships.
- 6. Educate Latino families about caregiving and identify the caregiver trainings available in English and Spanish.
- 7. Develop culturally and linguistically competent informational materials in multimedia platforms that addresses the specific needs of diverse caregivers.
- 8. Develop a systemic approach that builds the capacity of communities to address the needs of Hispanic caregivers.
- 9. Promote strategies that encourage employers to support caregivers so they can continue to work while caring for a loved one.
- 10. Provide training to caregivers of older adults and health care providers, so they can provide culturally, linguistically and age sensitive care to diverse elders.
- 11. Close health-related disparities among Hispanic older adults, their families and caregivers, especially in the areas of Alzheimer's disease, access to health insurance, quality healthcare and access to caregiver support programs and information.
- 12. Increase affordable and quality housing for seniors.
- 13. Strengthen financial programs for caregivers and families.

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## **Executive Summary**

ispanics are a remarkably resilient population. Hispanic older adults continue to face daunting challenges in the areas of retirement security, healthy aging, discrimination, housing and access to programs. They are struggling to age with dignity, often facing the specters of homelessness and hunger, as well as chronic disease. Yet, in the midst of these pressing challenges, they are eager to be civically engaged and are ready to share insightful and concrete recommendations to address the challenges they face.

This year, the National Hispanic Council on Aging (NHCOA), along with its partners, focused on the needs of Hispanic caregivers. This was illustrated over the course of the past year as NHCOA implemented a national caregiving survey, a series of regional conferences, and thought leaders round tables on caregiving. The Hispanic older adults and caregivers that participated in these events were enthusiastic about working to support caregivers and were dedicated to addressing the burdens of caregiving for Latino caregivers.

The challenges faced by Hispanic caregivers may seem daunting, but the dedication of community leaders, Hispanic focused nonprofit organizations, decision makers and experts working together can find solutions to the challenges and ease the burdens of caregiving for Hispanic caregivers. The following report documents the information gathered this year about the challenges faced by Hispanic caregivers and recommendations on how to overcome those challenges.

The first approach was the implementation of a literature review to compile the existing data on the state of Latino caregivers. The second approach was the implementation of a series of Regional Conferences designed specifically to elicit solutions to the pressing problems faced by the Hispanic caregivers. The third approach was a national survey conducted by NHCOA to understand who Hispanic caregivers are, the challenges they face and the resources they would like to have in Spanish. The following are summary results of each of these approaches to gain better insights into Hispanic caregivers needs in 2017.

### **Literature Review**

he literature review compiled data about caregiving as well as issues that came up at the regional conferences in 2017: retirement security, housing, health, and access to services and programs. Highlights from the literature review are summarized, by topic, below:

### **Older Adult Latinos**

- The most substantial common cultural value among Latinos of various national origins may be the high priority accorded to family. It is also the value that is most likely to remain in place regardless of migration and increased acculturation.<sup>1</sup>
- Additionally, multigenerational family living (defined by the Pew Research Center as a household that includes two or more adult generations) is rising fastest among Asians and Latinos.<sup>2</sup>
- The Hispanic population continues to expand, reaching a record 58.6 million in 2017, according to the Census Bureau's latest estimates.<sup>3</sup>
- It is projected that in 2060, the Hispanic population will reach 119 million, constituting 28.6% of the US population.<sup>4</sup>
- In 2014, 46.2 million Americans were aged 65 and older and it is expected that number will double by 2060.<sup>5</sup>
- Additionally, in 2014, there were 3.6 million older adult Hispanics, constituting 8% of the older population in the US; this number is expected to grow to 21.5 million by 2060, constituting 22% of the older population in the US.<sup>5</sup>
- The vast majority, almost 70%, of older adult Hispanics lived in just four states: California, Texas, Florida, and New York.<sup>5</sup>
- When examining self-rated health status, older adult Hispanics were less likely to report very good or excellent health (33% of older Hispanic men and 27% of older Hispanic women) when compared to older adult non-Hispanic whites (45% and 47%, respectively).<sup>5</sup>
- While most older adults suffer from at least one chronic condition, older adult Hispanics suffer from the following most frequently occurring conditions: hypertension, diagnosed arthritis, all types of heart disease, diagnosed diabetes, and cancer.<sup>5</sup>
- In 2013, it was reported that almost a ¼ of older adult Hispanics had both Medicare and a type of supplementary private health insurance, while 17% were covered by both Medicare and Medicaid. 5,6
- A higher percentage of older adult Hispanics (7% compared to other older adults 4%) also reported having no usual source of health care.<sup>5</sup>

### **Caregiving**

- Latino caregivers often embrace their role and view caregiving as an opportunity to give back to those who sacrificed for them.<sup>7</sup>
- Respect for elder autonomy, preservation of elder dignity, and maintenance of the elder's role within the family is a big value among Latinos. <sup>7</sup>
- Often Latino caregivers do not know where to turn for guidance, relief, and support for their caregiving activities.<sup>7</sup>
- Forty-five percent (45%) of Hispanics experience higher burdens from taking care of an elder or impaired family member, spending on average 32 hours per week compared to 33% of whites that spend 20 hours per week.<sup>7</sup>
- The average Hispanic caregiver:
  - o Is a 42.7-year-old female,
  - Provided care in the last 12 months, typically to a 65.3 year old female relative,
  - o Is not paid for the care provided, and
  - o Provides care without the assistance of paid help.<sup>8</sup>



- One of the main challenges among Hispanic caregivers is finding a balance between the needs of their loved one and the caregiver's financial situation. On average, Hispanic caregiver household incomes are \$38,600, well below the national median (\$54,700).
- Caregiving ranges from assistance with daily activities and providing direct care to navigating complex health care and social services systems. Caregiving includes assistance with household tasks, self-care tasks, mobility, provision of emotional and social support, health and medical care, advocacy, care coordination, and surrogacy.
- Long distance caregivers, who live at least 1 hour from the care recipient, are typically involved in providing social and emotional support, advanced care planning, financial assistance, and care-coordination. They often share these responsibilities with a more proximal caregiver who provides assistance with personal care.
- Hispanic caregivers are more likely to suffer from financial strain and emotional stress as a consequence of the high number of hours spent providing unpaid caregiving support.<sup>7</sup>
- The intensity and duration of caregiving and the older adult's level of impairment are predictors of negative health effects for the caregiver.
  - Other risk factors include:
    - Low socioeconomic status,
    - High levels of perceived suffering of the care recipient,
    - Living with the care recipient,
    - Lack of choice in taking on the

caregiving role,

- Poor physical health of the caregiver,
- Lack of social support, and
- Physical home environment.<sup>9</sup>

### **Housing**

- In 2015, the median family income of older homeowners was \$31,000. The median family income of older renters was \$17,400. In 2015, almost 44% of older householders spent more than one-third of their income on housing.<sup>10</sup>
- Homeownership rates vary widely by race and ethnicity. 82% of whites over the age of 50 own homes, compared to 58% of Blacks, 62% of Hispanics, and 70% of Asians.<sup>11</sup>
- According to Harvard's Joint Center for Housing Studies, more than 1/3 of Hispanics and Asians aged 80 and older live in households headed by a relative. 12
- Hispanics and Asian older adults are more likely than whites or Blacks to live in multigenerational households. 11

### **Retirement Security**

- Hispanic older adults are the least prepared segment of the U.S. population for retirement and are unlikely to have retirement savings of any kind. They often don't understand the retirement system and are more likely to return to the workforce to make ends meet if they are able. Because they were likely to have been employed in physical labor intensive jobs, they need re-training to return to work as older adults and in this process, they often face ageism when seeking employment
- In 2015, older adults averaged \$5,756 in out-of-pocket health care expenditures, an increase of 37% since 2005. In contrast, the total population averaged \$4,342 in out-ofpocket costs. Older Americans spent 12.9% of their total expenditures on health, compared with 7.8% of all consumers.<sup>10</sup>
- Just over 2.4 million older whites (6.6%) were poor in 2015, compared to 18.4% of older African-Americans, 11.8% of older Asians, and 17.5% of older Hispanics. 12
- In 2015, 51.5% of Hispanic older adults had social security benefits. 13
- In 2014, older adults reported the major sources of income as Social Security (84%), assets (62%), earnings (29%), private pensions (37%), and government employee pensions (16%).<sup>12</sup>

### **Medicare Fraud**

- There are 3 main ways scammers commit Medicare fraud on the Hispanic community:
  - o Billing for services or supplies that weren't provided,
  - o Stealing beneficiaries' Medicare numbers, and
  - o Sending medical equipment or products to patients who don't need them, patients accept products and services they do not need, and then patients are billed to Medicare.

- Hispanic older adults are vulnerable to Medicare fraud because of social isolation. Many Hispanic older adults are isolated from the general population due to a combination of factors, including linguistic and cultural differences and discrimination. This isolation may result in a lack of understanding.
- Another characteristic that may make Hispanics vulnerable to Medicare fraud is their
  cultural hesitance to report anomalies or to question suspicious practices. This is because,
  first, Hispanics hold especially doctors, with a great deal of respect. Second, they may have
  experienced repression in their home countries. Finally, there exists a fear of breaking a
  relationship with a healthcare provider resulting in limited options for care because of
  retaliation.

### **Health**

- Latinos face many health disparities, including high levels of food insecurity and lack of health insurance.<sup>14</sup>
- 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. <sup>14</sup>
- The top causes of death for Hispanic older adults are heart disease, malignant neoplasms, cerebrovascular diseases, pneumonia & influenza, chronic obstructive pulmonary diseases, atherosclerosis, diabetes mellitus, unintentional injuries, nephritis, chronic liver disease and cirrhosis.<sup>15</sup>

#### 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.<sup>16</sup>
- Latinos are about 1½ times as likely to have Alzheimer's or other dementias as older whites. 14,16
- 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.<sup>14</sup>
- The number of diagnosed cases of Alzheimer's among Latinos is only expected to rise, reaching an estimated 1.3 million Latino seniors by 2050. 14

#### HIV & AIDS

• The 1990s development of HAART (highly active anti-retroviral therapy) for the treatment of HIV is one of medicine's most dramatic success stories.<sup>17</sup>



- By the end of 2013, more than one million people in the United States have been diagnosed with HIV.
- The Centers for Disease Control and Prevention (CDC) reports that the rates of HIV among those over 50 years old is rapidly increasing.<sup>17</sup>
- Older adults may believe HIV is a young person's disease, however older adults should remember the risk factors for getting HIV are the same for older individuals as it is for young adults.<sup>17</sup>
- The rates of HIV/AIDS among people ages 50 and over in the United States were five times higher among Latinos compared to non-Hispanic Whites. 18
- In 2009, Latinos represented 16% of the U.S. population, yet accounted for 20% of HIV infection diagnoses. 18
- The rates of HIV/AIDS are disparately high among Latinos due to several factors, such as lack of information about HIV, stigma, late testing, and lack of access to care. 18

### **Access to Services/Programs**

- In the U.S., over 4.8 million low-income adults over age 60 rely on <u>SNAP</u> to stay healthy and make ends meet. On average, they receive <u>\$108 per month</u> to help put food on the table.<sup>19</sup>
- Three-out-of-five seniors who qualify for SNAP do not participate in the program. Meaning 5.2 million seniors miss out on benefits. Older Americans who qualify for SNAP are significantly less likely to participate in the program than other demographic groups. Many seniors face barriers related to mobility, technology, and stigma and are discouraged by widespread myths about how the program works and qualifies. <sup>19</sup>
- Hispanic caregivers often have limited access to programs or information to reduce their burden of care.<sup>7</sup>

## NHCOA Regional Conferences: Empowering Communities to Age with Dignity

HCOA implemented three regional conferences in 2017; 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 was 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 Hispanic caregiving. The goals of these conferences were to gather information about the role of Hispanic caregivers and how to effectively support them in their roles while also advocating for local and national level policies that reduce the financial, physical and mental burden of caregiving. These conferences featured panel discussions of key issues faced by Hispanic older adults and their caregivers which opened the floor to group discussions and possible solutions.

### Miami, Florida

## The key issues identified by Miami, FL community members are:

- Caregiving support,
- Affordable housing,
- Transportation,
- Homelessness,
- Poor infrastructure (vulnerable to impact of storms and hurricanes), and
- Access to health services



### Silver Spring, Maryland

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

- Caregiving support,
- Raising awareness about the needs of Hispanic older adults,
- Eradicating Hispanic older adult isolation,
- Transportation,
- Affordable housing, and
- Immigration.



### Los Angeles, California

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

- Financial burden on family caregivers,
- Access to quality health care,
- Need for formal training of family caregivers,
- Raise awareness about existing services and programs,
- Mental health, and
- Affordable housing.

## HISPANIC COMMUNITY MEMBERS' RECOMMENDATIONS FOR SUPPORTING CAREGIVERS FROM NHCOA'S REGIONAL CONFERENCES:

- Strengthen financial programs for caregivers and families.
- Educate Latino families about caregiving professions, and what caregiving services are available in Spanish and English.
- Provide trainings to caregivers of older adults and health care providers, so they can provide culturally, linguistically and age appropriate care to diverse seniors.
- Promote strategies that encourage employers to support caregivers so they can continue to work while caring for a loved one.
- Implement federal tax credits for family caregivers to offset the financial burdens associated with caregiving.



- Create and provide culturally and linguistically knowledgeable in-home social services offered at the county level.
- Create a "village of caregivers" that allows caregivers to come together to support each other.
- Reformulate poverty guidelines
  - o Many community members stressed that income and poverty guidelines are prohibitive when it comes to accessing social services and they do not take into consideration the financial burden of caregiving. These guidelines need to be more realistic and more supportive of middle income families.
- Create trainings for family caregivers to assist with stress relief and situational depression.



### **National Caregiving Survey**

n 2017, NHCOA implemented the National Caregivers Survey. It was administered in Spanish and English and could be taken online or in-person at various NHCOA Many local community-based events. organizations and community leaders were instrumental in disseminating this survey to survey takers. The target audience was Latino caregivers. participation voluntary Survey was and anonymous. The goal of the 2017 survey was to:

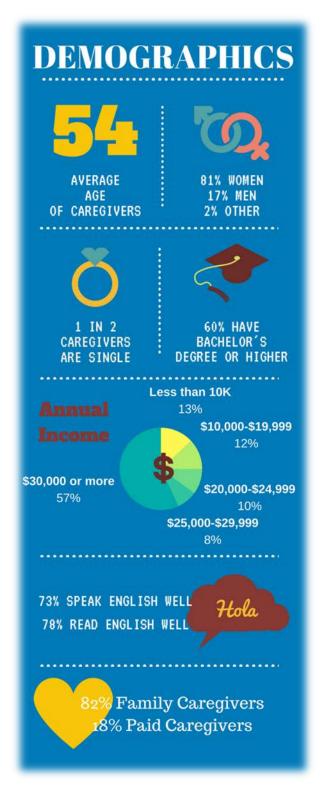
- Understand the demographics of Latino caregivers,
- Describe the challenges caregivers face, and
- Recognize what resources are needed to aid caregivers in their roles.

Over 7 months (March - September), NHCOA surveyed 158 Hispanic caregivers. Eighty-nine (89) participants took the survey in English and sixty-nine (69) participants took the survey in Spanish. One-in-four (25%) caregivers were age 65 and older, with an average age of 54. The age range of survey takers ranged from 26 years old to 82 years old.

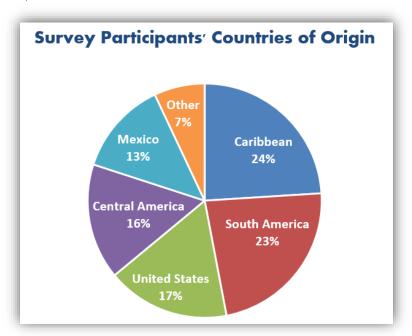
The vast majority of caregivers were employed (64%) and had incomes greater than \$30,000 (57%). More than 80% of Hispanic caregivers provided care for a friend or family member:

- ➤ Parent/Parent-in-law (50%),
- > Spouse/Partner (13%),
- > Child (12%),
- > Friend/Neighbor (8%), and
- > Other (31%).\*

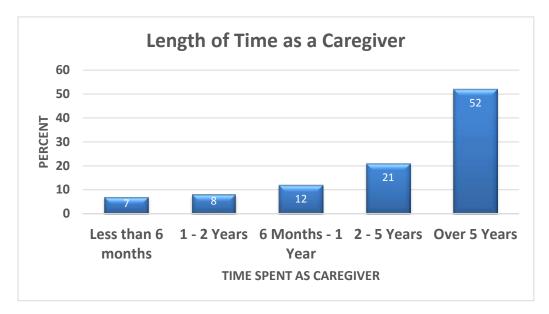
\*Note the percentages do not total 100% as caregivers could select multiple categories.



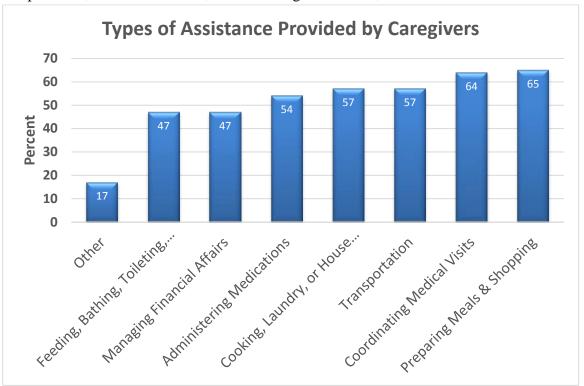
Survey respondents lived in 19 states, Puerto Rico and Washington, D.C. Most respondents live in Maryland (30%), California (16%) and Florida (15%), the sites of this year's regional conferences. Eighteen countries/territories of origin were represented by caregivers who took the survey, with most having been born in the United States (17%), Puerto Rico (13%), Mexico (13%), and El Salvador (11%).



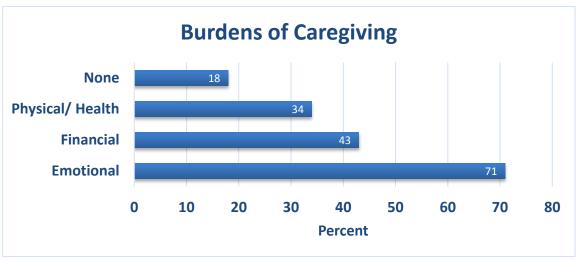
Half of caregivers live with the ones they are caring for and more than half (52%) of caregivers have been providing care for more than 5 years. Additionally, when we asked about the amount of time spent on caregiving, we found that 29% of caregivers spent less than 8 hours a week on caregiving, 22% spent 9-20 hours a week, 15% spent 21-30 hours a week, 11% spent 31-40 hours a week, and 23% spent more than 40 hours a week on caregiving tasks.



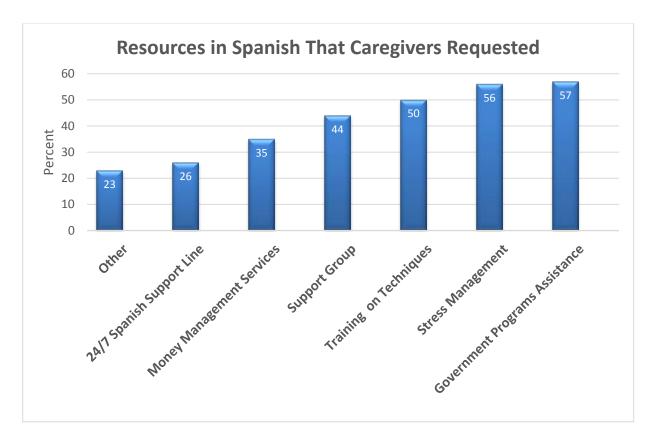
Caregivers provide a range of services and assistance for those they are caring for. To better understand the types of assistance that Latino caregivers currently provide to their loved ones, we asked "What kind of assistance do you provide?" Caregivers were able to select multiple services. Most caregivers tended to provide everyday assistance such as meal prep, assisting with medical visits, transportation, household chores, administering medication, etc.



Caregivers provide care to individuals with a variety of conditions including advanced age, dementia, and cancer. This experience can be a chronic stressor, and caregivers often experience detrimental psychological, behavioral, and physiological effects on their daily lives and health. Latino caregivers overwhelmingly reported (71%) that caregiving is taking an emotional toll on them.



Latino caregivers were asked to list their top three challenges they have experienced as a caregiver. Most caregivers (64%) reported that balancing other family and personal responsibilities was among their top three challenges as caregivers. Forty-four percent of Hispanic caregivers reported communicating with health care providers as a major challenge. Other challenges included finding information and educational resources for caregivers (47%), having enough money to afford caregiving (48%), and understanding government programs such as Medicare, Medicaid, SSI, SNAP, etc. (56%). We also asked caregivers about their changes in employment status due to their caregiving roles and found that slightly more than half (51%) had no change in jobs status. The major change reported was a decrease in hours, however, only 13% reported that change. This year NHCOA is working 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 to see assistance with government programs in Spanish (57%) and trainings on stress management (56%). Another major concerns among Latino caregivers is that many are untrained, and half of caregivers wanted the trainings on caregiving techniques in Spanish.



### **Pending Caregiving Legislation**

### Paid Leave Legislation: H.R.947 and S.337

Illness can require workers to take time off work for themselves or for loved ones. Currently, the United States, has a federal law, the Family and Medical Leave Act (FMLA), which entitles eligible employees to take unpaid, job-protected leave for specified family and medical reasons. However, this federally-guaranteed unpaid leave is not economically feasible, particularly if illness of an individual or their loved one incurs high healthcare costs. Paid family and medical leave is a key workers' rights issue across the nation. Workers need time to bond with new children, deal with personal illness, or care for an ill family member. Research has shown that paid family leave has little to no effect on work productivity or profitability. In fact, paid leave saves the national healthcare system money and has a positive effect on public health. Research also shows that abuse of paid leave programs is minimal.

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. In light of the growing number of intergenerational households and caregivers across diverse communities, NHCOA recommends a bipartisan passage of the FAMILY Act.

In light of the growing number 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 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 Caregivers Act S.1028**

Family caregivers provide unpaid assistance activities of daily living (eating, bathing, and dressing, toileting, transferring and walking) and instrumental activities of daily living (managing finances, transportation, shopping and meal preparation, house cleaning and maintenance, and managing medications and medical visits). Unpaid care provided by family caregivers is valued at ~ \$470 billion annually.

The RAISE Family Caregivers Act would require the development, maintenance, and updating of an integrated national strategy to recognize and support family caregivers. The bill would bring 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.

Latino low-income family caregivers spend about 44% of their income on Caregiving, therefore NHCOA is working to create awareness about the need to approve The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act.

"It is crucial that Hispanics become involved in this initiative to raise their voices in order to disseminate the impact of this bill. Representatives from both the private and public sector

would be part of an advisory body to make recommendations to the Secretary of Health and Human Services. Our goal is to propose a national strategy that supports and meets the real needs of Hispanic families who care for senior loved ones." - Dr. Yanira Cruz, President and CEO of NHCOA.

### **Other Advocacy Efforts**

This year we saw the U.S. Department of Health and Human Services (HHS) try to erase lesbian, gay, bisexual and transgender (LGBT) seniors from a key survey that helps HHS ensure its programs for seniors are reaching everyone and serving them well.

For the past three years, the National Survey of Older Americans Act Participants, conducted by HHS, has included LGBT-related questions so that when analyzing the results of the survey, policymakers and service providers could get a better sense of the particular barriers and discrimination that LGBT elders face when it comes to accessing the important services they need in order to age in dignity.

In March, HHS revealed that they would cease to ask any LGBT-related questions in the survey. This is serious because there is already a paucity of data on LGBT elders generally, and LGBT Hispanic elders in particular. And we know from our own research, released last



fall that many LGBT Hispanic older adults face both racial/ethnic and LGBT-based discrimination that prevents them from accessing quality housing and jobs, leading to greater poverty. This leads them to rely even more on the services of the Older Americans Act, such as meals, transportation, caregiver support, and senior centers.

We joined forces with Services and Advocacy for GLBT Elders (SAGE) to raise our voices in urging that HHS add LGBT questions back into its survey of

older adults. In response to the advocacy around this decision, HHS reversed itself in part, allowing LGBT elders to identify their sexual orientation however, it excluded the gender identity questions from the survey. This unfortunate move will leave out crucial data on transgender seniors and their unique struggles.

### **Sources Cited**

- 1. Velasquez RJ, Arellano LM, McNeill BW. The handbook of Chicana/o psychology and mental health. Mahwah, NJ: Routledge; 2004.
- 2. Cohn DV, Passel JS. A record 60.6 million Americans live in multigenerational households: Pew Research Center; 2016.
- 3. KROGSTAD JM. U.S. Hispanic population growth has leveled off. Washington, DC: Pew Research; 2017.
- 4. US Census Bureau. Hispanic Heritage Month 20162016.
- 5. Administration for Community Living. A Statistical Profile of Hispanic Older Americans Aged 65+. Washington, DC: US Department of Health and Human Services; 2015.
- 6. US Census Bureau. HEALTH INSURANCE COVERAGE STATUS BY AGE (HISPANIC OR LATINO): US Census Bureau; 2016.
- 7. National Hispanic Council on Aging. Proceedings from a thought leaders roundtable. Washingotn, DC: National Hispanic Council on Aging.; 2017.
- 8. National Alliance for Caregiving, AARP Public Policy Institute. The Hispanic/Latino Caregiver. Washington DC: NATIONAL ALLIANCE FOR CAREGIVING; 2015.
- 9. Families Caring for an Aging America: The National Academies of Sciences, Engineering, Medicine.: 2016.
- 10. Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. A Profile of Older Americans: 2016. Washington, DC: Department of Health and Human Services; 2016.
- 11. Joint Center for Housing Studies of Harvard University. HOUSING AMERICA'S OLDER ADULTS: MEETING THE NEEDS OF AN AGING POPULATION. Boston, MA: Harvard University; 2014.
- 12. Bipartisan Policy Center. America's Growing Senior Population: Assessing the Dimensions of the Demographic Challenge A Background Paper of the Bipartisan Policy Center Health and Housing Task Force. Washington, DC: Bipartisan Policy Center,; 2015.
- 13. Dushi I, Iams HM, Trenkamp B. The Importance of Social Security Benefits to the Income of the Aged Population. Social Security Bulletin 2017;77.
- 14. National Hispanic Council on Aging. 2017. Washington, DC: National Hispanic Council on Aging; Breaking stigmas, creating awareness, and increasing age-sensitive education are three key elements to improve the lives Alzheimer's patients and their caregivers.
- 15. National Center for Health Statistics. Health, United States, 2016: With Chartbook on Longterm Trends in Health. Hyattsville, MD: National Center for Health Statistics; 2016.
- 16. Alzheimer's Association. Alzheimer's Disease Facts and Figures: Alzheimers Dement; 2017.
- 17. National Institute on Aging. Aging with HIV: Responding to an emerging challenge. Washington DC: National Institutes of Health; 2013.
- 18. National Hispanic Council on Aging. NHCOA Encourages Hispanic Older Adults And Families To Talk HIV By Getting The Facts, Getting Tested, And Getting Involved. Washington, DC: National Hispanic Council on Aging; 2016.
- 19. SNAP and Senior Hunger Facts. National Council on Aging, 2017. (Accessed September 20, 2017, at https://www.ncoa.org/wp-content/uploads/Senior-Hunger-Fact-Sheet.pdf.)



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