Hispanic Family Caregiving:
Proceedings from a Thought Leaders Roundtable

I. INTRODUCTION

Caregiving among Latinos is often a natural occurrence in life and it is embraced by many with grace and sacrifice. It is often an opportunity to give back to those who have done so much for us. For generations, we have been taught the importance of respecting our elders, honoring their wisdom and being there for them in time of need. As a society, we have a great opportunity to leverage this foundation of the Latino culture and allow it to flourish so that caregivers can have all the necessary tools and information to care for their loved ones and themselves. Too often, Latino caregivers do not know where to turn for guidance, relief, and support for their caregiving activities. NHCOA and its partners seek to understand the various needs caregivers have, and develop a program that offers the education and training necessary to construct a network of caregivers that is well equipped and informed in order to serve their loved ones.

As the older adult population continues to grow exponentially, the need for caregivers becomes more pressing. Caregiving can take a significant toll on a person, and compared to non-caregivers, family caregivers of older adults are more likely to experience emotional distress, depression, anxiety, and/or social isolation. According to the National Academies of Sciences, Engineering and Medicine study on Families Caring for an Aging America, some caregivers reported being in poor physical health and some have elevated levels of stress hormones or higher rates of chronic disease. This situation is even more challenging for Hispanic caregivers, who spend almost 32 hours per week caring for a loved one; many of them also have full time-employment, and have to carry on with the rest of their lives and families.

“My biggest challenge as a caregiver is the lack of information on how to care for my mom and improve her life. My mom has diabetes and sometimes she gets depressed because she wants to live a normal life. I do my best to support my mom because I love her and she is my mother, but it is not easy because I work, I am married, I have two kids, and sometimes I don’t know what to do or where to go for help.” This is the testimony that a caregiver shared during the NHCOA Thought Leaders Roundtable.

Understanding the challenges and needs of Hispanic caregivers goes beyond the traditional approach as “caring for Latino elders is considered an honor and a role that family members perform willingly.” In other words, exploring the reality of caring for a loved one among Latino communities requires being aware of the culture, beliefs and traditions that determine the relationship between the caregiver and the recipient.

In 2015, out of the 43.5 million people that have provided unpaid care to an adult or child during a twelve month period, 9.1 million were Latinos. In other words, non-white Hispanic caregivers
have the highest reported prevalence of caregiving among any other race or ethnic group at 21\% (African Americans 20.3\%, Asian Americans 19.7\%, and Whites 16.9\%).iii Usually, family caregiving is understood as an unpaid task that involves assisting a loved one with activities related to daily living (ADLs) and/or medical tasks, such as giving medication, preparing meals, feeding, housekeeping, assistance in the bathroom, transportation, coordinating physical visits and managing financial matters.iv This is very significant as 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.v Consequently, 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 as on average, the Hispanic caregiver household income is $38,600, well below the national median ($54,700).vi Hispanic caregivers are more vulnerable to suffer from financial strain and emotional stress as a consequence of the high number of hours spent providing caregiving support.

Hispanics are also more likely to be a primary caregiver and more reluctant to send their older adults to nursing homes or assisted living. This can be related to many causes, such as a) the belief that the patients could be mistreated at assisted homes; b) the belief that not accepting the role of caregiver could bring shame on the family; and c) the understanding of caregiving as a shared responsibility among relatives, especially female siblings.vii These considerations are crucial to successfully develop a national strategy that helps support Hispanic caregivers.

The purpose of this report is to share the proceedings from the Caregiving Thought Leaders Roundtable held in Washington, DC on February 14, 2017. The roundtable focused on identifying the education and training needed to support Hispanic caregivers. The discussion was based on a new study released by the National Academies of Sciences, Engineering and Medicine (NASEM) focusing on Family Caregiving for Older Adults. The information gathered from the convening will inform NHCOA’s national strategy on family caregiving and create awareness on caregiving among Hispanics.

II. DISCUSSION

The roundtable was opened by NHCOA’s President/CEO Dr. Yanira Cruz, welcoming remarks were offered by AARP’s Vice President, Multicultural Leadership, Yvette Peña, moderated by Dr. Octavio Martinez, NHCOA Chairman and Executive Director of the Hogg Foundation for Mental Health, and closing remarks were done by the John A. Hartford Foundation Sr. Program Officer Marcus Escobedo. A diverse group of 40 experts on Family Caregiving participated in the roundtable. Organizations and partners participating in this roundtable included, AARP, Alzheimer’s Association, Caregivers de Puerto Rico, Compassion & Choices, DH/Perfil Latino TV, Eldercare Workforce Alliance, Family Values @ Work, Hogg Foundation for Mental Health, Institute of Medicine, John A. Hartford Foundation, Labor Project for Working Families, Latinos Against Alzheimer’s Coalition & Network, Mary’s Center, Maryland Department of Health and Human Services - Area Agency on Aging, Montgomery County – Aging and Disability Resource Unit, Office of Minority Health, PhRMA, and SAGE.
Participants identified a series of solutions to improve education and training among Hispanic family caregivers, as well as ways to close the gap between resources available and specific Hispanic caregivers’ needs. The following section details participants’ insights:

**A. Contextual realities in caregiving among Latinos**

- Caregivers experience financial instability and lack of savings and/or retirement funds. For Latinos, this becomes a augmented reality, given their financial instability.
- Latinos are less likely to utilize formal ways of caregiving because of costs and the lack of awareness on resources available.
- Limited time, lack of support, and exhaustion due to having to perform several roles (i.e. worker, parent, spouse,) while caring for their sick loved ones.
- Lack of data to document the problems caregivers face, especially about Hispanics and other diverse communities.
- Lack of information for family caregivers facing financial, geographical, and linguistic hardships. Even if information is available, the dissemination channels are not reaching multicultural communities.
- Lack of a national strategy that addresses systemic challenges facing caregivers.
- Lack of unified efforts to successfully reach diverse caregivers with education and information on support programs and services.
- Caregiving stigma prevalent among Latinos prevents them from seeking financial, relief or mental health support. Latinos perform their caregiving activities as natural roles in their lives and feel uncomfortable asking for help.
- Latinos lack information regarding programs, services and support available for caregivers.
- Family caregivers fear that asking for help might jeopardize them and increase the risk of being forced to put their loved ones in an institution.
- The use of the right language is important. When we say family caregivers, we leave out many caregiving realities not involving relatives by blood.

**B. Three Most Important Recommendations**

Participants shared their insights and recommendations, and the top three priorities identified were the following:

1. Creating a caregiving hub for different organizations to feed into and spread awareness on services available for family caregivers.
2. Framing caregiving as a multigenerational issue that affects all communities, not just older adults.
3. Partnering with Latino expert organizations to develop programs and services that meet Hispanics’ specific needs, strengthen the community, and help to build trusted relationships.

C. Recommendations

- Strengthening financial programs for caregivers and families is crucial, especially for diverse communities.
- Educating Latino families about caregiving as a profession, and the services available in English and Spanish.
- Developing information that addresses the specific needs of diverse caregivers and making it available through culturally and linguistically competent channels.
- Developing a systemic approach to addressing the particular needs of Hispanic caregivers. Making systemic changes to build communities’ capacity to support family caregivers.
- Use a multigenerational approach to ensure older adults, young adults and youth are included in the educational efforts.
- Creating a caregiving hub to provide information and resources for Latinos.
- Creating a 24/7 toll free line in English and Spanish to respond to family caregivers questions and concerns.
- Develop programs to break the stigma among the community and advocate for the allocation of resources to increase education and information among Hispanics about programs available for caregivers.
- Provide training to caregivers of older adults and health care providers, so they can provide culturally, linguistically, and age sensitive care to diverse seniors.
- Disseminate information using culturally, linguistically, and age sensitive channels to reach diverse caregivers. For instance:
  - Partnering with Latino organization that are experts on reaching the community
  - Levering on community health workers to help close the gap of caregiving among hard-to-reach communities. For example, developing a red of local champions to help engage and serve local community members
  - Using communication channels such as radio and TV
- Promote strategies that encourage employers to support caregivers so they can continue to work while caring for a loved one.
- Develop programs that support the mental health of caregivers such as:
  - Support groups
  - 24/7 toll free support line

III. CONCLUSION

This roundtable was an opportunity to bring together leading aging organizations and professionals to discuss the realities of family caregivers, especially among diverse communities. This was a productive discussion and the proceedings set the stage for promoting a local and national discussion to address this issue. There are key points that came out of this discussion including:

a) The need to understand Hispanic caregivers (i.e. who they are and their specific needs)

b) A great need to conduct research (primary and secondary) to document the reality of Hispanic family caregivers and to develop programs and services to target this specific population.

c) Framing caregiving as a multigenerational issue and reaching out to younger generations, who also need support and resources.

d) Viewing caregiving as a community issue and seeking ways to develop support and connections in a broader spectrum.

e) Developing implementation strategies to bring information to this population in a culturally and linguistically appropriate manner.

In summary, conducting research to document the reality of Hispanic caregivers, and the contributions they are making to their families, communities, and society is critical to crafting strategies that are culturally, linguistically, and age sensitive to support their caregiving efforts. National and local organizations play a decisive role in the process of disseminating information and creating awareness about the need for more data, resources and services available for Hispanic family caregivers. NHCOA and the participating organizations look forward to continuing the conversation and help to support Hispanic family caregivers.

IV. REFERENCES


iv Ibid.

v Ibid.
