It, Too, Takes a Village
Caregiving for Metro Denver’s Latino Elders
A Report for Colorado Latino Age Wave - 2014

“We know the Latino community has much strength in how they influence outcomes. Respect for family and older adults is still a cultural strength—one that needs to be identified and fortified.”

Maria Aranda, Ph.D.
Associate Professor of Social Work
University of Southern California
AARP Caregiving Advisory Committee
Colorado Latino Age Wave is a flagship project of the Latino Community Foundation of Colorado. The mission of Colorado Latino Age Wave is to invest in and advocate for innovative services and programs that support the well-being of Denver’s Latino older adult population and their family caregivers. This report was made possible from support by the Colorado Health Foundation, Community First Foundation and Rose Community Foundation.

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Colorado Latino Age Wave is a project of the Latino Community Foundation of Colorado (LCFC) and was launched in October of 2011. In partnership with Colorado Health Foundation, Community First Foundation, Hispanics in Philanthropy, and Rose Community Foundation, the mission of Colorado Latino Age Wave is to invest in and advocate for innovative services and programs that support the well-being of Denver’s Latino older adult population and their family caregivers.

This report for Colorado Latino Age Wave examines the emerging knowledge about the role of family caregiving for Latino elders across Metro Denver. While the term “caregiver” is not in the vocabulary of most Latinos, most Latino families embrace the cultural tradition of keeping their elder loved ones within their homes and their communities while tending to their needs for as long as possible. Often, several generations in the same family share a roof and accept caregiving roles, thus transmitting cultural values about elders and aging from generation to generation.

Through its work in the community, Colorado Latino Age Wave perceived a growing urgency related to the stresses faced by caregivers of Latino elders and their families. The stresses are especially acute for adult women who often become exhausted by attempting to meet the needs of children, grandchildren, and elders while also working, homemaking and staying afloat financially. The acuteness of these stresses for Latino caregivers were a clear indication that the support systems in place for older adults in Metro Denver were inaccessible and/or underutilized by Latinos. Caregiving responsibilities are absorbed by the elders’ families—especially the primary caregivers—with little outside help.

Why are Latino elders and their caregivers not getting more help? What are their experiences in seeking or utilizing outside support? How could support systems better meet the needs of Latino elders and their caregivers? How can the cultural assets of the Latino community serve as an example for how non-Latino elders can “age in community?”

This report unites two lines of inquiry to better understand caregiving of elders in Metro Denver’s Latino community:

• A summary of field research conducted across Metro Denver. In late 2013 and early 2014, seven focus groups with 84 total participants were held to identify shared concerns and suggest potential solutions related to caregiving in the Latino community.

• Connections between the initial assessment data, field research and observations by professionals who know the field of aging from various professional perspectives: academia, philanthropy, health care and human services. Those interviewed also have personal experiences as caregivers for elder loved ones.

A final section is a set of next steps.

We hope this report will lead to a robust, better-informed discussion about the role of caregiving in Metro Denver’s Latino community. We look forward to supporting future actions that strengthen the vital role that caregivers play within and beyond the Latino community.

Carlos Martinez
Executive Director
Latino Community Foundation of Colorado
Introduction

Toward a New Model of Aging
Aging in Community

This is the “new” gold standard for almost everyone concerned with aging, from gerontology professionals, to service providers, to policymakers, to those whose voices matter most: older adults themselves.

“Aging in community” simply means living to the end of your life surrounded by the people you know, in a community where you belong, with activities you enjoy, the possessions you value, and even the food you like to eat. People aging in community inevitably change as infirmities accumulate. To age in community requires that your living environment—and those who share it—must adapt to changes brought on by aging.

Remaining independent until the end of life is an increasingly acute challenge. Advances in health care allow people to live years or decades longer, even in poor health. Age-related illnesses often require ongoing specialized treatment and more intensive home-based and/or institutional care. In addition, the sheer number of older adults who need outside help is growing rapidly and will force a shift in how American society addresses aging.

“Caregiver” is a relatively new word in the English language, first appearing in a social work text in 1966 according to the Oxford English Dictionary. (It replaced the antiquated “caretaker,” more associated with property than with people.) Americans have quickly adopted “caregiving” into their vocabulary to describe the paid or unpaid work of caring for children, elders and the disabled.

“There is no equivalent word in Spanish for ‘caregiver.’ People just understand ‘this is my role so of course I am going to do this.’”

Maria Aranda, Ph.D.
Associate Professor of Social Work, University of Southern California
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“The term ‘caregiver’ is not part of the lexicon in the Latino community,” says Dr. Maria Aranda, associate professor of social work at the University of Southern California and member of AARP’s Caregiving Advisory Committee. This fundamental difference in language indicates a cultural gap that is increasingly apparent with the rapid growth of the Latino population in certain regions, including Metro Denver.

Long-held cultural values about family and respect for elders make it possible for Latino elders to age in community across the economic spectrum. This is not a new model for aging. Rather, it is a tradition with important lessons about family and community supporting elders.

“We are a community that takes care of our own and that is the good news.”
Cec Ortiz
Project Manager, Colorado Latino Age Wave
The fastest growing demographic in Metro Denver is people over 55. Based on the 2010 census, Metro Denver had 596,178 people age 55 or over. Of these, 11% or 63,690 were Latino. However, from 2000 to 2010 the number of Colorado Latinos 55+ rose 76.9% compared to 51.9% for all races in the same age group. By 2030, Latinos of all ages will increase by 174% compared to a projected 31% rise among white non-Latinos. The proportion of Latinos in the older adult population will continue to rise rapidly and indefinitely.

The Colorado Latino Age Wave 2012 Community Assessment identified two prevailing realities that prevent Latino older adults from receiving needed services.

The Community Assessment also articulated three critical components of cultural relevance in serving Latino elders.

To fulfill its mission, Colorado Latino Age Wave understood that its work had to focus on building awareness of Latino cultural values related to aging, to invest in efforts to increase cultural relevance, and shift public policy to make services more accessible.

Meanwhile, Colorado Latino Age Wave’s community outreach began to reveal an underlying urgency in an unexpected way: the critical role of the caregiver. Many conversations turned to the challenges that working adults face in caring for their elders.

“What we were hearing, and what research shows is that Latino families are often on their own, accepting a larger share of caregiving responsibilities for their elders,” says Cec Ortiz, Colorado Latino Age Wave’s project manager. “When Latino families who are striving for a better life lack support in caring for their elders, the result is more personal, household and financial stress. When support is inaccessible or not culturally relevant, Latino families pay a steeper price.”
Caregiving in Focus
A Deeper Look at Latino Caregiving in Metro Denver

In 2013, Colorado Latino Age Wave’s Community Advisory Committee adopted caregiving for Latino elders as a focal point for research and action. Anecdotal evidence of the prevalence of caregiving was abundant, however no formal research had been undertaken locally. The 2008 “Evercare® Study of Hispanic Family Caregiving in the U.S.” is a comprehensive study that informs Colorado Latino Age Wave’s approach. While it addressed some key issues, its data was neither local nor timely.

Colorado Latino Age Wave engaged Lori Ramos Lemasters, principal of Care Partners Resource, to conduct a series of focus groups of adult caregivers for Latino elders across Metro Denver. The purpose of this initial research was to gain a baseline understanding of family caregivers, the elders they care for, and to identify key issues facing caregivers, elders and families for further research.

(Note: Unless otherwise noted, the term “caregiver” in the context of this report refers to the unpaid caregiver for a Latino elder. Most often the caregiver is also Latino and a family member or other loved one.)

Care Partners Resource conducted a series of seven focus groups; five were held in September and October 2013, two were held in February and March 2014. Groups were held in Aurora, Longmont, Commerce City, Lakewood, Wheat Ridge and at two sites in North Denver. Participants from several nearby communities also attended. A meal was furnished at each focus group and participants were given a $50 gift card as compensation for their time and input. Upon request, free elder care was offered. When appropriate, a Spanish interpreter was provided. One focus group was organized for Spanish-only speakers. Another was organized for caregivers either working in, or retired from, professional careers.

Altogether, 84 individuals participated in the seven focus groups. The aggregated data does not capture responses from all 84 individuals because some participants did not complete the questionnaires that were distributed. In addition to seeking quantitative demographic data about the caregivers, all focus groups were asked a series of open-ended questions designed to encourage discussion on attitudes, challenges, rewards and stresses of caring for their elder loved ones.
Data About Caregivers and Elders

**Age**: Caregiver participants were about equally divided between those over 50 and under 50. Seven out of ten elders were 71 or older and 45% were over 80.

**Caregiver Gender and Relationship to Care Receiver**: The 87% female to 13% male ratio of Latino caregivers was even greater than the 74% female caregivers reported in the Evercare study. More than half of Latino caregivers were caring for an elderly parent.

**Health Problems of Latino Elder**: Diabetes and kidney-related diagnoses were the single most cited health issues for the elders receiving care at 22%. A number of elders had multiple diagnoses. “Other” encompassed a variety of conditions including cancers, arthritis, fractures and behavioral health.

**Employment**: 54% of caregivers worked outside the home and 46% did not work (n=74).

**Health Insurance**: 46% of caregivers had no health insurance, 22% were enrolled in public health insurance, and 32% had private insurance (n=56). 17% of care recipients were uninsured, while 53% had public health insurance and 30% had private insurance (n=74).

**Veteran Status**: 12% of Latino elders were veterans (n=58); 97% of Latino caregivers were not veterans (n=74).
A National Perspective on Latinos and Caregiving

The caregiver role poses difficulties for people from all walks of life, but Latino cultural values add layers of nuance and complexity. The 2008 “Evercare® Study of Hispanic Family Caregiving in the U.S.” identified a number of characteristics that differentiate caregiving within the Latino community from caregiving in a non-Latino context. Although these findings are now somewhat dated and are based on national research, they provide valuable guidance to understand the cultural, social and economic context for caregiving issues facing Metro Denver’s Latinos in 2014.

• Primary caregivers were more likely to live with the loved one they cared for (43% Latino vs. 32% non-Latino).
• More than one-third of households (36%) reported having at least one family caregiver. Along with secondary caregivers, the report estimated 8,147,000 Latino caregivers in the U.S.
• Household incomes were significantly lower. More than half (52%) of Latino caregivers (in 2008) lived in households earning less than $30,000 versus only 19% of non-Latino caregivers.
• Almost three-fourths (74%) of Latino caregivers were female. (This statistic doesn’t vary significantly from the caregiving demographic across mainstream and diverse populations.)
• Latino caregivers were more likely to be in “high burden” caregiving situations than non-Latinos (63% vs. 51%) and spent more hours per week providing care (37 hours vs. 31 hours). They also assisted in more activities of daily living, or “personal care” functions (2.6 hours vs. 1.9 hours).
• Eighty-four percent of Latino caregivers believed that their role is an expectation of their upbringing, and 70% thought it would bring shame to their family to not accept the caregiving role (vs. 60% of non-Latinos).
• Four in ten working Latino caregivers reported making a major change in employment such as taking a leave of absence, changing jobs, cutting back hours or stopping work entirely.
• Nearly three-fourths of Latinos (73%) felt that Spanish-language information and materials are important. More than three-fourths of caregivers (78%) felt that services delivered in Spanish are important.
• Latino caregivers were only half as likely (43% vs. 81%) to search for information on the Internet.
• Four out of five caregivers felt that a training class on caregiving duties would be helpful.

Critical Issues
Access to Services, Especially Transportation and Respite Care

As mentioned previously, the Colorado Latino Age Wave 2012 Community Assessment identified access to services as one of the primary barriers Latino elders face everyday. The focus group participants verified this information and identified two especially critical issues they confront as caregivers: transportation and respite care.

On March 27, 2014, Colorado Latino Age Wave invited participants in the seven focus groups to reconvene for a report back about the findings. A representative from Colorado Latino Age Wave reiterated that the goal of the initiative is to enable older Latinos to age in community and stay in their own homes. To be successful, Latino caregivers need additional support, services and resources. However, their needs often go unrecognized because Latinos typically accept caregiving responsibilities and the sacrifices they require as “part of life.”

Care Partners Resources made a presentation to the group about the identified critical needs: access to services with a particular focus on transportation and respite care. Transportation had been identified among many issues in the 2012 assessment; the need for respite care support emerged as a critical need through the focus group research, often expressed by caregivers as excess stress, isolation and lack of time to care for one’s self.
As each issue was presented, participants were asked to provide additional information and feedback about each, summarized below.

**Access to Services and Resources:** Many caregivers are thrust into the role suddenly with no preparation and are overwhelmed. Knowledgeable professionals in the aging field believe that Metro Denver has an adequate amount and variety of services to support elders, caregivers and families. However, caregivers face barriers and challenges in finding out about, and gaining access to the services they need and for which they qualify.

- For many Latinos, the lack of Internet access and/or computer skills prevents them from gaining access to information online.
- Language barriers present significant barriers to access.
- Service providers have not invested in culturally relevant marketing and outreach strategies that are effective in reaching Latino families. For example, most Latinos don’t respond to the term “caregiver,” even when professionals in the aging field define the duties they are performing as “caregiving.”
- Like most people, Latinos prefer to receive and act on information from trusted sources—family members, faith organizations, neighbors and others.
- Immigration status is often a barrier for entire families. If one or more family members are undocumented, the threat of discovery is a deterrent from seeking help for which the elder and his/her family may qualify.
- Caregivers and families are often unable to proactively manage their elder loved one’s care because they lack knowledge of both problems and solutions. Some report that health providers do not spend the time necessary to educate elder patients and caregivers about how to manage a disease or disability, or how to avoid the next crisis.
- Focus group participants expressed a desire to have a one-stop location to go to find out about services and programs to help them. They expressed an interest in the community-based promotoras model and navigation services to help them learn about and access appropriate services. (Promotoras are residents and identified leaders in their communities who are trained to provide health education and connections to services.)
Latinos and the American Way of Aging

For mainstream Americans, aging in community hasn't always been a choice, or even a term in general use. For earlier generations, it was simply a way of life. For the most part, families from all walks of life cared for their elders at home until they died in their own beds, or after a brief final hospitalization.

In the prosperous years following World War II, aging began to change dramatically for mainstream Americans. Family structures changed and dispersed in response to expanding educational and economic opportunities. American society structured its housing, employment, education and services around a generally young, prosperous and mobile population living in cities and suburbs. Aging adults who could afford it accumulated savings to safeguard their independence throughout retirement, not wishing to burden loved ones with their care. Social Security and Medicare have provided several generations of older adults with at least a safety net, if not an extra cushion of support to maintain their independence.

Over the past half century, caregiving for older adults has become a growth industry in the American social mainstream. Those who can afford caregiving services have a wide assortment of options: retirement communities, assisted living, skilled nursing facilities, home health care and a multitude of auxiliary services.

The aging systems and services in community today were created by and for people who are American-born, mostly white and middle class. They have shaped policies, programs and services around social and cultural values held by a longstanding majority. Today, and for the foreseeable future, the aging population encompasses more people of color, many of them born outside the U.S., and not acculturated to prevailing American values around aging, family and caregiving.

Simply stated, Latinos are aging in a social and cultural context that they did not help create.

Critical Issues (continued)

Transportation: Various transportation services are available to serve older adults and people with disabilities including InnovAge, RTD, RTD Access-A-Ride, Seniors Resource Center, and low-cost taxi coupons. However, participants cited numerous problems with transportation services:

- Medicaid provides transportation services, but people do not know how to access the service. Callers may spend a long time on hold waiting for help.
- RTD is less responsive to the needs of low-income neighborhoods, a fact documented by 9to5 Colorado in a January 2014 report entitled “Left at the Station.”
- Eligibility for services depend on insurance, distance, provider and even whether you have a social worker who can help you get the kind of service you need.
- Spanish speakers in attendance said they couldn't find out anything about transportation services and relied on each other to provide rides.
- Services are often unreliable. Spanish speakers ordering Access- A-Ride or similar services often reach dispatchers who don't speak Spanish. Some older adults report being stranded when vehicles they ordered did not arrive. Long waits for service were also cited as reasons they did not use these services.
- The “Getting There Guide,” a publication of the Denver Regional Mobility and Access Council, provides comprehensive information about senior transportation in print, by phone and online. It is available in Spanish as “Guía de Como Llegar.” No one present was aware of this information service.
- Participants suggested several places where transportation information in Spanish could be made available: churches, grocery stores, Medicaid offices and recreation centers in Latino neighborhoods.
Critical Issues (continued)

Respite Care: Family members who care for an elder often do so at the expense of their own well-being and that of their immediate families. Respite care provides either a paid or unpaid caregiver for the elder so primary caregivers can take care of their own needs. While there is a variety of adult day care programs available, participants were either unaware of the services or cited problems with them.

• Many of these services are not affordable for low-income families.
• Adult day care programs operate during nine-to-five business hours during the week. This scheduling does not fit the working lives of many Latinos.
• Services provided by adult day programs are often not aware of or sensitive to the cultural preferences of Latino elders. In care facilities, this extends to details such as the food served, the décor, even the background music.
• Elders often do not accept in-home assistance from anyone who is not a family member, and especially from care providers whose ethnicity, language and demeanor are outside of the elder’s experience.
• In general, Latinos do not trust nursing homes or assisted living centers to provide quality care for their elders. Lower-cost facilities that are affordable for many Latino families are perceived as being substandard and often are.
• Hospice care for elders near the end of life is not yet widely embraced by Latinos. Hospices are not perceived to offer culturally relevant services.
• In certain situations, Medicaid allows health care consumers to pay family members to provide care. However, the hourly rate is very low and it is for a very limited number of hours. Few people know about it, and the process required to obtain this benefit is complicated.

The findings of the focus group research and the additional feedback provided by participants at the March 27, 2014 report-back meeting offers solid direction for additional research and analysis.
A Big Shift
Adopting an Asset-Based Cultural Model

Latinos and other ethnic and cultural groups tend to reject the prevailing American norms in aging. “Latinos may be acculturated to the American way of life in most ways,” says Ortiz. “But when it comes to how our families pitch in and care for our elders, we just aren’t following the script.”

Latinos living in American society risk compromising this treasured cultural value as a result of pressures to blend into a social fabric shaped by the historically white, middle-class majority. This includes the American way of aging, complete with its inherent (though mostly unintended) cultural limitations and social biases. This includes a preference to “lessen the burden” of elder care on families by professionalizing it and/or delegating it to institutions.

Meanwhile, the aging of nearly 80 million baby boomers is forcing an increasingly urgent discussion about resources. The costs of professionalizing and delegating elder care are incalculable given the sheer numbers of people who will require care throughout an extended period of physical and mental decline. That is why “aging in community for as long as possible” is taking shape as a new standard. And that is why support for community-based and family-centered caregiving must rise as a priority in public policy, program development and resource allocation.

What does a different future look like? “It might look more like the way Latino families and communities embrace the rewards and responsibilities of caring for their elder loved ones, but with more social support,” says Ortiz.

Social supports could include resource centers that help foster multigenerational and culturally sensitive neighborhoods focused on helping everyone to thrive in their homes. Resources offered could include volunteers, promotoras and outreach efforts to distribute useful information. Health services would come to the patient. More families would take advantage of a Medicaid program that provides modest compensation for a family caregiver giving up to 32 hours of care per month. More people would be covered by the federal Family and Medical Leave Act, which provides up to 12 weeks annually for employees to take uncompensated time off from work to care for a family member without risking their jobs.
Who will be the caregivers of the future? With the retirement of the baby boomers, a thriving economy will draw more people into the work force to replace retirees, even as these older people will require more care. The Bureau of Labor Statistics predicts that from 2012 to 2022, the nation will need nearly 600,000 new personal care aides. Many will be from other nations.

“With the increasing emphasis on aging in community for everyone, Latinos have a lot to offer,” says Ortiz. “Care for elders has to be organized differently with families, friends and communities coming together to share responsibilities and create networks of support. The Latino community is the natural place to start.”
In the coming year, Colorado Latino Age Wave will focus its efforts on five key areas of work incorporating the report findings.

**Community Awareness**
Expand a campaign to increase awareness of how to best serve Latino elders and their caregivers to provide culturally competent care.

**Caregiver Education**
Develop presentations, focus groups and workshops on the challenges and policy issues that affect Latino elders and family caregivers.
Gather additional information about Latino family caregivers’ knowledge and receptivity to seeking out and receiving respite care information and support.
Conduct research with family caregivers to understand their most pressing needs and develop tools to help them address day-to-day care management concerns.
Create a family caregiver toolkit to train service providers and caregiver professionals.
Initiate strategic partnerships with key service providers whose focus is serving Latino elders and their family caregivers.

**Grantee Cohort**
Work with its current grantee cohort to remove barriers and increase the access to services for Latino elders and their caregivers.

**Policy Building**
Educate policy makers and other stakeholders on policy issues that impact Latino elders and their caregivers.

**Technical Assistance**
Deliver culturally appropriate technical assistance services to Latino and aging service organizations.
The Latino Community Foundation of Colorado is an initiative of Rose Community Foundation. Our mission is to influence and engage Latinos and others as leaders and philanthropic investors in developing strong and vibrant Latino communities in Colorado.

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