Master Plan
Research Summary

January 31, 2014

Table of Contents

Introduction

In developing the Master Plan for Aging Services Delivery, several research protocols were used to identify the needs for senior services in Washoe County. These activities included the following:

- Random Survey of 600 Community-Dwelling Seniors
- Focus Groups
- Interviews with Select Population Groups
- Two Public Listening Sessions
- Guided Conversations on Information and Referral and Transportation

This report provides highlights from each of these research activities.

Highlights from the Random Survey of 600 Community-Dwelling Seniors

A total of 600 citizens were interviewed by telephone for the 2013 Washoe County Senior Needs Assessment Survey. The sample was derived from a random digit dialing (RDD) methodology within the designated 775 area code rather than from a listed sample or voter-based sample. This included both unlisted numbers and phone numbers of seniors who are not registered to vote. The random distribution of respondents in terms of age group, gender, race/ethnicity, and geographic area was roughly proportionate to the 2013 County population as a whole.

The study was launched on August 14, 2013 and completed by August 31, 2013. The survey was conducted in English. The overall response rate of eligible, qualified respondents who completed the survey was 31%. The sampling error for the survey is $\pm$ 4%. Sara Hart, Ph.D. of InfoSearch International managed the survey and prepared the final report.

In planning for this survey, the team had some theories about vulnerable senior groups' awareness and need for services. We designed the survey instrument to explore these theories. The groups thought to be most vulnerable were: low-income, those age 80 and over, minorities, and those who were frail or socially isolated. Note: 99% of seniors surveyed live in the community outside of a group home, assisted living facility, or nursing home.

Economic Security

In nearly all indicators, those with annual incomes of less than $30,000 were economically more vulnerable than those with higher incomes. A couple with an annual income of $29,693 is at 185% of the federal poverty level. The findings from the survey support this vulnerability:

- Over 41% of seniors in Washoe County have an annual income of less than $30,000. This equates to approximately 33,100 seniors. Nearly one in ten (9%) report incomes of $10,000 or less. Nearly three in five (57%) of minorities report an annual income of less than $30,000.

- About one out of four respondents (26%) indicated that their rent or house payment costs more than 30% of their monthly income or about 21,000 persons. 4% had gone without heating, cooling, and/or water in the prior year because they could not afford it (estimated to be 3,400 individuals age 60+). Minorities are significantly more likely than Caucasians to say they have gone without their utilities because they could not afford them.
- Overall, 11% did not seek medical care in the prior year due to cost (that equates to approximately 8,900 individuals).
- One out of ten (10%) or about 8,100 persons had gone without some or all of their medications in the prior year because they could not afford it. More females than males report that they have gone without taking some or all of their medications due to cost (13% vs. 7%).

- 12% of seniors said they did not have enough money to pay their bills in the past year; this equates to approximately 9,700 individuals.
    - Households with annual incomes of less than $30,000 were significantly more likely than those with higher incomes to say they did not have enough money to pay their bills (26% vs. 4%).
    - Similarly, those considered moderately to highly frail reported that they did not have enough money to pay their bills (18%). Likewise, those who are considered moderately to highly socially-isolated were more likely that those not isolated to have said they have problems paying their bills (19% vs. 7%).
    - Minorities are significantly more likely than Caucasians to report that in the last year they did not have enough money to pay their bills (20% vs. 10%).

- Women are significantly more likely than men to have incomes lower than $30,000 per year (49% vs. 31%). Nearly two-thirds (63%) of women who are unmarried have incomes of less than $30,000 per year.

Frailty

Frailty is a key contributor to institutionalization. Using several questions asked in the questionnaire, the researcher designed a frailty index to define the level of frailty. Those respondents who are most vulnerable (due to health status and other physical limitations) were designated as moderately to highly frail.

- 28% of respondents were categorized as moderately or highly frail. This equates to approximately 23,000 individuals' age 60+.
    - Projecting to 2023 there may be 30,000 seniors who are considered frail, and by 2032, this number may jump to 35,600 seniors.
    - 39% of those age 80+ are considered frail
    - 46% of those seniors with an annual income of less than $30,000 are considered frail.
    - Those who are moderately or highly frail are less likely to be aware of community support services.
- 26% of seniors said their health status was either fair or poor. This equates to 21,000 individuals who may be at risk of institutionalization in the next five years.
- 27% of seniors had fallen in the prior year, (about 22,000 individuals in the past year) Falls can lead to increasing frailty and compromise an individual's ability to remain independent.
- 3% of respondents needed assistance with two or more Activities of Daily Living (ADLs) (about 2500 individuals). ADLs are defined as "the things we normally do...such as feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure. Those ages 80+ are

significantly more likely than those younger to have problems with bathing, grooming, and taking medications.

- 15% of respondents said they experienced periods of depression, (12,100 individuals). Although the sample is very small (n=43). 42% of those with incomes of less than $10,000 per year indicated they had experienced problems with depression.

Social Isolation

Like frailty, social isolation can also be a contributor of institutionalization. Seniors who are socially isolated may not have access to a range of services that may help detour institutionalization such as social engagement, health and pharmacy services etc. According to the survey, one in four seniors in Washoe County is moderately to highly socially-isolated.

- 25% of seniors were deemed to be moderately to highly social isolation. This equates to approximately 20,000 seniors.
    - 42% of seniors age 80+ are considered socially isolated.
    - 37% of unmarried seniors are socially isolated.
    - 40% of those with annual incomes of less than $30,000 per year are also considered socially isolated.
- 6% of those who are age 80+ do not leave their home in a typical week; 8% of those who are frail and 15% of those who are socially isolated do not leave their home in a typical week.
- Notably, 14% of those age 60+ no longer drive, this equates to approximately 11,300 individuals who are dependent on other forms of transportation to get to where they want and need to go.
- However, seniors continue to contribute to their community through community engagement. 44% of seniors volunteer. This equates to 36,000 seniors.

Caregivers

Caregivers, especially those who are providing care to a senior with dementia, are especially vulnerable. For them, caregiving is a 24/7 proposition. Some report getting less than three hours sleep per night. Their need for caregiving support and information is dramatic. Those caregivers interviewed for the survey represented a relatively small proportion of the survey sample (9% or n=52).

- Among the sub-group of caregivers, one out of four or more of these seniors reported needing assistance with emotional care (29%), respite care (28%), financial support (27%), and/or housekeeping (27%), while 12% needed assistance with providing personal care.
- About one out of five caregivers (19%) reported that they had major debt due to caregiving.

Awareness and Usage of Community Services

There is a wide array of services available in the community that helps to support independence and avoid institutionalization for seniors. Unfortunately, a large percentage of vulnerable seniors are unaware of the services and do not use them.

- Of all listed services, all vulnerable groups are most aware and likely to use Senior Centers.
- Two in five or more of seniors age 80+ are unaware of the range of services available to support their independence.
- Other than Senior Centers, a third or more seniors who are moderately or highly frail are unaware of community support services. The same is true with those seniors who are moderately- to highly- socially-isolated; nearly half or more of these seniors are unaware.
- Seniors whose annual income is less than $30,000 are only slightly more likely to use services than the other three vulnerable groups.
- Of all vulnerable populations, those ages 80+ are the most likely group to be unaware of services.

For specifics on the service awareness and usage of community services by population category, refer to Table 1 on the following page. The full report on the survey is included on the webpage found at http://www.washoecounty.us/seniorsrv/MP/MasterPlan.htm.

Table 1

Use and Unawareness of Core Senior Support Programs By Vulnerable Senior Groups

Category of Service	Income <$30,000/yr.		Age 80+		Moderate/High Frail		Moderate/High Socially Isolated	
	Aware & Used	Unaware	Aware & Used	Unaware	Aware & Used	Unaware	Aware & Used	Unaware
	%	%	%	%	%	%	%	%
Home Delivered Meals	5	36	4	61	6	48	6	49
Senior Nutrition Program	5	54	4	69	4	64	4	67
Food Stamps	21	34	2	60	15	42	15	47
Adult Day Care	1	54	1	61	0	60	0	65
Senior Center	**32**	**21**	**23**	**40**	**26**	**27**	**19**	**30**
Respite Services	2	69	1	75	1	74	1	75
Homemaker Program	3	77	2	83	2	81	3	85
Public Transportation like Access	11	32	11	48	12	37	9	45
Counseling or Mental Health Services	6	58	3	69	7	59	6	63
Care Coordination or Case Management	3	73	1	77	4	77	2	83
Representative Payee Services	1	77	0	79	1	79	1	83
Low-income Energy Assistance	15	41	3	70	9	53	10	56

Highlights from Focus Groups

The survey yielded useful information on key issues. To explore issues in more depth, a series of focus groups were convened to "listen" to experiences and stories consumers had to share about their needs. The focus groups fall into three categories: topical groups, special populations, and providers. It is important to learn the issues consumers and providers when attempting face to develop a comprehensive strategic plan.

The topical issues assigned to focus groups were: Active Living, Basic Needs (transportation, housing and food security), Caregiving/Home and Community-Based Care, Economic Security and Labor Force Participation, and Health and Safety. These issues are the core categories of needs that were discussed in the Stakeholder Groups.

The second collection of focus group reports are called Special Populations. These include: age 85+ population, Hispanic, LGBT, and Rural. Other focus groups have been convened for African- and Asian-Americans. For the African- and Asian-Americans groups only one person showed up at each of these groups. There were two sets of focus groups for each of these population groups, but there were too few persons to host a group. The Master Plan team decided to conduct one-on-one interviews with persons from these groups as opposed to convening additional focus groups. The team also attempted to set up a focus group with Native Americans. The process was slow to materialize. It was decided to conduct one-on-one interviews with Native American leaders and to conduct one-on-one interviews with Natives Americans. Five were conducted. The interviews will be overviewed in a separate report is on the Webpage at http://www.washoecounty.us/seniorsrv/MP/MasterPlan.htm.

The third category of focus groups involved service providers. There was one group of health care providers and another of advocates who represent seniors' interests and concerns at the local level. Two guided conversations were also held. Two key themes emerged through both the consumer and provider focus groups: transportation and information and referral. One guided conversation included the state and local ADRC coordinator and the local SHIP coordinators. While the guided conversation on transportation involved two RTC professionals.

The purpose of all of these research activities was to identify actionable items that would help seniors to address the varied problems that they face due to caregiving responsibilities, health and mental health problems, low incomes, isolation and the lack of available programs and information resources. The conversations in the Focus Groups underscore the complexity in communicating the availability and benefits of services because of the unique needs of each senior and each caregiver. It appears that the smallest complexity, exacerbated by the lack of essential services and a fragmented service delivery system, can create insurmountable barriers to seniors who are ill, frail, socially isolated or otherwise challenged by the demands of aging.

The following is a list of the key recommendations emerging from both the consumer and provider focus groups. These have been organized by the six core issues being studied as part of the Master Plan. Consumer priorities include the following:

Consumer's Priorities

Active Living

- Organize a senior-to-senior buddy program designed to reduce feelings of isolation.
- Expand the availability of lesbian, gay, bisexual, and transgender based social networks and groups.

Basic Needs (transportation, nutrition, and housing)

- Expand affordable transportation options in Washoe County with particular emphasis on un-served and underserved areas.
- Expand transportation options available during evening hours.
- Increase funding for Section VIII and other senior housing options.
- Investigate options for converting currently unused buildings into senior housing.
- Investigate ways that city planning can encourage the reestablishment of neighborhood communities.
- Organize handyman services to assist seniors to maintain their homes, especially in rural areas of the County.
- Expand funding for Meals on Wheels and increase the amount of food available in each meal to ensure that clients can have more than one meal a day.

Health/Caregiving/Safety

- Explore options for providing low-cost dental services to low-income seniors.
- Encourage the inclusion of dental coverage under Medicaid.
- Explore options for increasing the availability of low-cost medications for seniors.
- Investigate strategies for making eye care services more affordable.
- Investigate ways to make health care more affordable to low- and moderate-income seniors.
- Washoe County should educate Senators and Congressional Representatives on the specific needs of caregivers and push for research and demonstration projects.
- Advocate for increased funding for Alzheimer's disease and dementia research at the state and federal level.
- Consolidate and dissemination information on available sources for financial support for respite care.
- Explore the development of a co-op of caregivers who are willing and able to assist with temporary respite care.

- Investigate whether Washoe County can supplement available sources of financial support to pay for respite care services.
- Investigate what other states are doing to assist caregivers with the financial costs of respite care.
- Investigate and advocate for financial assistance for low- and moderate-income families who provide care in their homes; analyze what other states are doing to provide financial support to family caregivers.
- Investigate what training and information is needed to support caregivers; determine the most effective strategies for disseminating the information; and launch educational initiatives that are focused on their training needs.
- Improve access to home and community-based care services to those living in rural or isolated areas of Washoe County.

Home and Community-Based Care/Long-Term Care

- Develop a pamphlet or resource guide on the comparative costs of various levels of care; disseminate the guide to families making decisions about long-term care options.
- Explore options for a volunteer-supported respite care program.
- Create standards for measuring and improving the quality of care provided by home care workers.
- Examine how other states have addressed the issue of high turnover rates among in-home care workers.
- Advocate for the expansion of Medicare/Medicaid coverage for home and community-based services.
- Increase access to home and community-based services in rural areas.
- Consolidate information on respite care facilities and promote its availability through a variety of methods.

Workforce Participation

- Expand support programs for seniors returning to work after long-term unemployment.

Other

- Explore strategies for updating and upgrading the Aging and Disability Resource Center (ADRC) I&R program.
- Improve the accessibility of caregiver resources and materials.
- Investigate strategies for consolidating information on activities and volunteer opportunities and disseminate the information through a variety of vehicles.

- Investigate how information can become more accessible to isolated seniors and their families.
- Increase public information about what Washoe County Senior Services does and the types of information and resources available.

Health Care Provider's Priorities

Providers were also asked to indicate what their priorities were:

- Refine information available through Information and Referral (I & R) Centers to enhance their ability to help seniors locate services that best meet their needs
- Fully staff I and R Centers so that seniors seeking services always deal with a "live" staff member rather than a recording.
- Create a network of services so that providers can easily share key client information.
- Create a website on state laws and regulations to help providers become informed of requirements.
- Create incentives for professionals and para-professional to work in the health care field.

Advocate's Priorities

A group of advocates were convened to share their perspectives on what the top priorities were. Their top priorities include:

- Upgrade and coordinate information resources beginning with problem-solving the ARDC website.
- Expand transportation

These issue areas were provided to the Stakeholder Groups for use in their deliberation on the proposals being developed for inclusion in the Master Plan for Aging Services Delivery. Full text for the Focus Group reports appears at http://www.washoecounty.us/seniorsrv/MP/MasterPlan.htm.

Highlights from Interviews with Select Population Groups

Participation of diverse populations in the focus groups was a high priority. However, recruitment of African-, Asian- and Native Americans proved extremely difficult. We successfully recruited participants for both the African-American and the Asian American focus groups; however, only one person for each showed up for the meeting even though confirmations were made either by telephone or email. We offered a second meeting time for each with the same result. We used a variety of recruitment tools including engaging community partners in recruitment, churches and other religious groups, invitations posted at all congregate meal and

community center sites, and one-on-one solicitations at the senior centers. We worked through the various local tribes to set up a focus group for Native Americans but that never materialized.

Given that insights from these key groups were needed, one-on-one interviews were conducted with African and Asians-Americans. For Native Americans, we interviewed tribal leaders to assess needs. These were supplemented through one-on-one interviews with Native American citizens.

The issues that were mentioned as top concerns by the groups were consistent with those emerging out of the focus groups:

- ***African Americans***
  - Employment
  - Information and Referral
  - Home and Community-Based Care Services
  - Food Insecurity
  - Health Care

- ***Asian Americans***
  - Health Care
  - Translation Services

- ***Native Americans***
  - Transportation
  - Health Care
  - Food Insecurity
  - Loneliness

- ***Compared to Caucasians***
  - Health Care Coordination
  - Dental Care
  - Transportation
  - Information and Referral
  - Home Maintenance
  - Civic Engagement

Highlights from One-on-One Interviews with Service Providers

To inform the Master Plan Team about the situations confronted by service providers, face-to-face interviews were conducted with a range of service providers in the following areas:

- Assisted Living Facilities/Independent Living Facilities

- Skilled Nursing Facilities
- Adult Day Care
- In-Home Services
- Information and Referral agencies
- Employment agencies
- Housing representatives
- Legal services
- Hospices
- Case managers
- Educational Programs
- Various planning and support agencies

The initial questions in the interview were designed to assess the profiles of the agencies/businesses. All but one of the programs interviewed primarily serve persons age 50+, and all but one are easily accessible to the public. 70% of these programs rely on referrals to obtain clients. Only four of the agencies interviewed have waiting lists with the average wait period being between three and six months. Costs for services vary from $19.50 per hour to $2,800 per month. Only six of the agencies offer a sliding fee scale. Two-thirds of the agencies indicated an interest in expanding their services. However, only three have developed budgets for expansion.

The second set of questions used in the interviews were about any challenges they experience in delivering services.

Providers were provided a list of five concerns and asked if any were challenges in delivering services: lack of resources, high caseload, lack of consumer knowledge, cost of services, and difficulty accessing services. Among these concerns, the top two were lack of consumer knowledge and lack of resources.

Table 2

Percent Indicating a Problem with Five Service Delivery Issues

Challenge	% Yes
Lack of Resources	51%
High Caseloads	29%
Lack of Consumer Knowledge	57%
Too Expensive for Senior Clients	20%
Difficult for Seniors to Access	29%

Providers were asked if they collaborate with other providers in delivering services. All said yes and indicated that they believed that the collaboration enhanced the quality of their services. Next, they were asked if they experienced any difficulties in collaborating with other groups. One in five indicated that there were problems. Issues mentioned included: legal restrictions; age restrictions; lack of understanding about the scope of their services; confidentiality restrictions, such as HIPPA; and lack of awareness of the agencies with whom they could coordinate.

The providers were also asked whether there were any policies, regulations or laws that interfered with their ability to collaborate with other providers. One in four respondents said there were, and they identified the following concerns:

- State law regulating who can give injections
- Inconsistent rules and regulations
- Inconsistent application of rules and regulations by inspectors and auditors
- Need for consumer education on services and support systems
- General lack of coordination among oversight agencies
- Medicare and Medicaid only allow one payer source each time
- Limited understanding of providers about dementia

Finally, providers were asked what changes they believe should be made to improve their ability to provide services. Numerous issues were identified and included the following:

- Broaden definition of what constitutes health care model
- More education for caregivers/teach caregiving in schools
- Reduce inappropriate institutionalization and overuse of services
- Increase in staff pay scales/increase available workforce
- Coordination of transportation services
- Increase funding for aging services
- Increase communication and coordination among service providers
- Enact legislation to reduce complexity of laws and regulations
- Ensure consistent application of laws, regulations, and policies
- Increase awareness of the availability and scope of services
- Improve information and referral services

Highlights from Interviews with Native American Leaders

Service Needs:

To assess the needs of the Native American population, interviews were conducted with top executives at three of the local health organizations. The questions asked in the interviews were

similar to those asked of providers in the focus groups. Key issues that were identified as problems for Native Americans were consistent with other Washoe County consumers, but were exacerbated by the very low incomes of the Native American population. Issues identified included the following:

- Transportation
- Limited access to services
- Preventative Health Services
- Chore Services
- Home Health Services
- Homemaker Services
- Case Management
- Limited specialty health care

Administrative/Legal Barriers:

Each of the participants identified barriers to services. They included the following:

- Complex service applications are a barrier for tribal members in applying.
- HIPPA represents a serious challenge to tribal members. Historically, there have been attempts to erase the Native culture, and this has made it very uncomfortable for Native Americans to share information. They simply do not want to relay on others outside of their tribe.
- Complex Medicare regulations make it somewhat difficult to work with other service providers.
- There is lack of coordination with Washoe County Senior Services.
- There is limited access to nutrition funding under OAA Title III funds because the program calls for providers to have a commercial kitchen, even when small numbers of persons attend the meals.

Full transcripts from the interviews with the Native American leaders appear in the Focus Group Report contained at http://www.washoecounty.us/seniorsrv/MP/MasterPlan.htm.

Highlights from Two Public Listening Sessions

Thus far in the Master Planning Process, two public listening sessions have been held to encourage the public and other interested parties to comment on the goals, purpose, and activities of the Master Plan. They made their recommendations for what topics should be included in the Master Plan. A general meeting was held on October 16th. On November 21st, a meeting was held to solicit input on the proposed priorities.

Three major themes emerged in the first meeting:

- The need for improved access to transportation.
- The need for caregiver resources, i.e., financial, training, and respite services.
- The importance of partnering with other community organizations to provide services while managing limited community resources.

At the second session, attendees were presented a ballot that listed the objectives emerging through the Stakeholder Group deliberations and asked to rank their top five priorities. Note: The Stakeholder Groups identified 18 objectives and 90 specific tasks. In considering what made sense to include in the Master Plan, the decision was made to limit the objectives to no more than 12 proposals making it more likely that focused efforts could be achievable.

The participants identified their top five priorities as:

- Initiate a full-spectrum of senior transportation services that meet the needs of senior residents in Washoe County.
- Expand services to include integrative programs of physical, social, and mental health to maintain aging in their home and community.
- Explore strategies to improve transportation services to hubs of active living activities.
- Support the development of affordable senior housing options, including a spectrum of senior adult living facilities that are close to needed resources.
- Increase seniors' awareness about currently available home and community-based care.

These priorities were shared with the Stakeholder Groups prior to the meeting where they ranked their top ten priorities.

Highlights from Guided Conversations on Information and Referral and Transportation

It became clear early in the review process that the top two priorities for the Master Plan would be Transportation and Information and Referral. These topics were discussed in every focus group and in every Stakeholder Groups as well as the individual interviews. To better understand both the operations and the challenges experience by providers of these services, we held guided discussions with informed representatives from local service providers.

Transportation

Two key questions discussed with the Regional Transportation Commission (RTC) representatives were:

- What services are provided to seniors?
- What are the challenges that you face in serving seniors?

When asked how RTC specifically supports senior transportation, they said:

"In a variety of ways. 2 million senior or disabled riders on the fixed route out of 8 million and on ACCESS 200,000 people and most are either seniors or disabled. There are also resources applied to Roadway Improvement, Sidewalk Accessibility, and Intersection Improvements. All of these efforts contribute to the safety of seniors."

Two challenges were also identified by the representatives:

- Funding

"Funding is a particularly big challenge in the transit operating side. Because of the recession, there has been a lack of revenue from sales taxes. We do receive $20 million dollars from sales taxes and an additional $6 million from fares."

- **Multiple Disabilities**

"When you start talking about aging, you don't have just one disability, you have multiple disabilities. To meet the needs of seniors, we are adding more bike lanes, better lighting, getting buses that are easier to get on and off of, wider intersections, and circulator routes for outlying areas."

A full transcript of the discussion with RTC representatives is contained in the Focus Group Report that is included at http://www.washoecounty.us/seniorsrv/MP/MasterPlan.htm.

Information and Referral

As in the transportation guided discussion, participants were asked what their key challenges to delivering services were:

- **Staffing and Funding**

Lack of staff that is needed to do the work, time is always our enemy…Lack of funds is always a problem.

- **Seniors Themselves**

….you are dealing with people's specific problems…when you need something, it is not always there. We don't want them giving up. We want to do less referring. Another challenge is working with the seniors themselves. Seniors tend not to be comfortable with technology and they are cautious by nature. It is a problem to get seniors to buy into us….the bottom line is that it is a challenge to get them to trust. Some medical conditions are very touchy subjects. We also have a problem reaching rural residents.

When asked about outreach efforts, all three participants indicated there are problems due to limited funding and staff.

A full transcript of the discussion with the Advocacy and Disability Resource Center (ADRC) and SHIP representatives is included in the Master Plan Focus Group Report that is included on the Webpage located at http://www.washoecounty.us/seniorsrv/MP/MasterPlan.htm.

Master Plan
Focus Group Reports

December 2013

Prepared by:

Anita Stowell-Ritter

Michael Lam

Victoria Royeton

Table of Contents

Executive Summary

Washoe County Senior Services is currently developing a Master Plan on Aging Services Delivery. As part of the process, several research activities have been undertaken to collect data to inform the deliberations and the goals and task development.

The first research strategy was conducting a random-digit dial survey of 600 Washoe County residents age 60+. The survey yielded useful information on these key issues. It revealed that the many vulnerable seniors, those who are low income, socially isolated, frail, and age 80+ are unaware of community long-term services and support that can help them remain independent and reduce the future demand for more costly services.

To explore causative factors for low utilization and explore the issues in more depth, a series of focus groups were convened to "listen" to experiences and stories consumer have to share about their needs. The focus groups fall into three categories: topical groups, special populations, and providers. It is important to learn the issues confronted both by consumers and providers when attempting to develop a comprehensive strategic plan.

The topical issue focus groups were on: Active Living, Basic Needs (transportation, housing and food security), Caregiving/Home and Community-Based Care, Economic Security and Labor Force Participation, and Health and Safety. These issues are the core categories of needs that are being discussed in the Stakeholder Groups.

The second collection of focus group reports is called Special Population. Several focus groups have been held. They include: age 85+ population, Hispanic, LGBT, and Rural. Other focus groups have been convened for African-Americans and Asian. Two groups each have been convened for these populations, only one person showed up at each of these groups. The Master Plan team has decided to conduct one-on-one interviews with persons from these groups as opposed to convening additional focus groups. The team has also been attempting to set up a focus group with Native Americans. The process has been slow. It was decided to conduct one-on-one interviews with Native leaders and to conduct one-on-one interviews with Natives. Five have currently been conducted. The interviews will be overviewed in a separate report.

The third category of focus group involved service providers. There was one group of health care providers and another of advocates who represent seniors' interests and concerns at the local level. Two guided conversations were also held. Two key themes emerged through both the consumer and provider focus groups: transportation and information and referral. One guided conversation included the state and local ADRC

coordinate and the local SHIP coordinators. While the guided conversation on transportation involved two RTC professionals.

The purpose of all of these research activities has been to identify actionable items that would help seniors to address the varied problems that they face due to caregiving responsibilities, health and mental health problems, low incomes, isolation and the lack of available program and information resources

The conversations in the Focus Groups underscore the complexity in communicating the availability and benefits of services because of the unique needs of each senior, each caregiver. It appears that the smallest complexity, exacerbated by the lack of essential services and a fragmented service delivery system, can create insurmountable barriers to seniors who are ill, frail or socially isolated or otherwise challenged by the demands of aging. The following is a listing of the key recommendations emerging from both the consumer and provider focus groups. These have been organized by the six core issues being studied as part of the Master Plan.

Consolidated Recommendations Emerging from Focus Groups

Consumer Priorities

Active Living

- Organize a senior-to-senior buddy program designed to reduce feelings of isolation.
- Expand the availability of senior transgender and lesbian social networks and groups.

Basic Needs (transportation, nutrition, and housing)

- Expand affordable transportation options in Washoe County with particular emphasis on un-served and underserved areas.
- Expand transportation options available during evening hours.
- Increase funding for Section VIII and other senior housing options.
- Investigate options for converting currently unused buildings into senior housing.
- Investigate ways that city planning can encourage the reestablishment of neighborhood communities.
- Organize handyman services to assist seniors to maintain their homes, especially in rural areas of the county.
- Expand funding for Meals on Wheels and increase the amount of food available in each meal to ensure that clients can have more than one meal a day.

Health/Caregiving/Safety

- Explore options for providing low-cost dental services to low-income seniors.
- Include dental coverage under Medicaid.
- Explore options for increasing the availability of low-cost medications for seniors.
- Investigate strategies for making eye care services more affordable.
- Investigate ways to make health care costs more affordable to low- and moderate-income seniors.
- Washoe County should educate Senators and Congressional Representatives on the specific needs of caregivers and push for research and demonstration projects.

- Advocate for increased funding of Alzheimer's disease and dementia research at the state and federal level.
- Consolidate and dissemination information on available sources for financial support for respite care.
- Explore the development of a co-op of caregivers who are willing and able to assist with temporary respite care.
- Investigate whether Washoe County can supplement available sources of financial support to pay for respite care services.
- Investigate what other states are doing to assist caregivers with the financial costs of respite care.
- Investigate and advocate for financial assistance for low- and moderate-income families who provide care in their homes; analyze what other states are doing to provide financial support to family caregivers.
- Investigate what training and information is needed to support caregivers; determine the most effective strategies for disseminating the information; and launch educational initiatives that are focused on their training needs.
- Improve access to home and community-based care services to those living in rural or isolated areas of Washoe County.

Home and Community-Based Care/Long-Term Care

- Develop a pamphlet or resource guide on the comparative costs of various levels of care; disseminate the guide to families making decisions about long-term care options.
- Explore options for a volunteer-supported respite care program.
- Create standards for measuring and improving the quality of care provided by home care workers.
- Examine how other states have addressed the issue of high turnover rates among in-home care workers.
- Advocate for the expansion of Medicare/Medicaid coverage for home and community-based care.
- Expand the availability of home maintenance services to rural areas.
- Increase access to home and community-based services in rural areas.

Workforce Participation

- Expand support programs for seniors returning to work after long-term unemployment.

Other

- Explore strategies for updating and upgrading the ADRC I&R program.
- Improve the accessibility of caregiver resources and materials.
- Consolidate information on respite care facilities and promote its availability through a variety of methods.
- Investigate strategies for consolidating information on activities and volunteer opportunities and disseminate the information through a variety of vehicles.
- Investigate how information can become more accessible to isolated seniors and their families.
- Increase public information about what Washoe County Senior Services does and the types of information and resources they have available.

Provider Priorities

Providers were also asked to indicate what their priorities were:

- Refine available Information and Referral Centers to enhance their ability to help seniors locate services that best meet their needs.
- Fully staff I and R Centers so that seniors seeking services always deal with a "live" staff member rather than a recording.
- Create a network of services so that providers can easily share key client information.
- Create a website on state laws and regulations to help providers interpret and implement requirements.
- Create incentives for professionals and para-professional to work in the health care field.

Advocate Priorities

A group of advocates were convened to share their perspectives on what the top priorities were. Their top priorities include:

- Upgrade and coordinate information resources beginning with problem-solving the ARDC website.
- Expand transportation.

These issue areas were provided to the Stakeholder Groups for use in their deliberation on the proposals being developed for inclusion in the Master Plan for Aging Services Delivery.

The following section of this report provides transcriptions from the various focus groups, with the exception of the Hispanic Focus Group. This Group was conducted in Spanish and was developed by notes collected by the facilitator.

Topical Focus Group Reports

Active Living Focus Group Report

September 27, 2013 1:30-3:00 pm

The focus group was designed to address the concerns seniors have with engaging in active lifestyles and community engagement. There were four focus group participants; three were currently very active in the community and one older woman was somewhat engaged. Of the four, two were men and two were women. One lived alone and the other three lived with spouses.

When asked about common activities that they do outside of the home, participants listed mat/chair yoga, pick-up ball, ball-room dancing, charity work, gambling, walks, tours with senior centers and church activities. In fact, all the people mentioned one form or another of a church activity and walking; whether it is to walk the dogs, or just walking outside. Another member stated that she just completed the **Fit, But Not Forgotten**, a VA Program for disabled veterans. She indicated that when you complete the classes, you get one free year at the gym.

When asked about health conditions that slow them down, one individual stated she had arthritis:

"I have arthritis and it's really all over….. I sometimes get fatigued but most of the time, our activities keep us going nonstop… our calendars are really full… I do feel fatigue from arthritis you know, and it interferes a little bit but not a lot, because I find it more enjoyable just to get out there…. you know to see whatever you can."

Another participant explained that she has COPD:

"The main thing is it's not just the COPD, I'm working on my third pacemakers, and I also have something called cardiomyopathy. Sometimes I get really tired even though I haven't done anything. I just make myself do things. I feel much better just lying at home, but I miss the activity. I miss the people. At my age, I'm 86, you tend to slow down."

While another participant who is still working full-time explained:

"I think the only thing that limits me these days is not enough hours in the day. I look forward to going to work."

Another respondent pointed out that some of the activities are limited not just her but some seniors in general because driving at night is very difficult and not always very safe to do.

The participants were then asked about how much time they are able to spend with their friends outside of the house. One respondent stated:

"I've reconnected with friends that I haven't seen in a long time that are still in town."

Participants were asked about their specific social engagement activity that they regularly do. Some of the things they do to give back to the community include Knights of Columbus (A Catholic fraternal organization that does charity work), volunteer work for the City of Reno, donations to the VA, Experience Workshops at local prisons (a three-day long workshop where the inmates are encouraged to think of the people around them, to have alternatives to violence), church volunteer programs, and education series (surrounding physical health) at medical facilities. One individual works to help the poor eat better and take care of themselves.

Two of the four participants stated that they felt activities in Reno for seniors are very affordable. They went on say that there are a lot of undiscovered volunteer opportunities for seniors in the community as well.

The participants were also asked about social media they use. One individual uses it a bit for access to family photos. Another is signed up but cannot figure out how to use Facebook citing it is too complicated, and two people do not use it at all, one respondent saying:

"I never understood that. I never got into it. I'm not that good with computers."

There was a lot of discussion when asked about barriers for seniors learning about and accessing social activities and community engagement activities in the local area. A couple of the participants feel there is a lot to do in Reno but people do not know what options exist. One person said:

"The information needs to be put out there in a different way than what it's being put out now."

Another participant got more in depth and explained:

"One thing I don't understand is why more seniors aren't involved with the city of Reno social programs. I don't know if they are not getting the word or they don't have the means to come or if they are alone and won't come by themselves….I don't know if there is a better way to get the information to the people. I believe that the elderly should not be alone and I believe that there's a way that once they come to a program that they might be able to see the value and just love it and come again, because there's a time that they will not be able to learn or volunteer. At that point, they should probably enjoy social activity. They've volunteered, they worked, and they've taken care of everybody so at one point they should be good to themselves and just take advantage of the wonderful social events that are available."

The older of the respondents explained how she felt fear was a factor that contributed to older seniors not engaging in society saying:

"its fear, it's almost like being a teenager and you don't know anybody and you want to go but getting in with a new group is sometimes difficult."

Participants were asked about the positives of community engagement and one person stated:

"If a person is alone of a certain age, they can volunteer. If they volunteer at one of these functions, they won't feel alone because they are doing the activities with their hands setting up something. They are not alone anymore because they are part of a group setting up something."

Transportation for seniors was touched upon a bit as well. One woman discussed ACCESS (a bus service for the disabled and seniors):

"I have a friend that uses it. It's a wonderful thing for people. Its $3 for a ticket, they will take you anywhere in town."

Another participant added:

"Maybe it might be worth looking into having a lecture at Washoe Senior Center or Reno Senior Center on alternative transportation."

Some of the individuals gave their personal views about volunteering offering some insight such as:

"I think that volunteerism is absolutely the entry into the last part of your life."

Also:

"I think if you can get into social activities that it will bring people back to life. Instead of inviting someone to something and saying this is what we need you to do…. I think the message needs to be you don't have to do anything. We just want you to be here. "

One individual also explained that:

Our culture has changed… we have more of a transient life, where neighborhoods feel disconnected. City planning might be causing the disconnection where neighbors do not know each other, and have less unity.

He went on to state:

"The thing I was thinking of is something probably the county certainly can address well by itself is how the demographic, how the world has changed, and how this town has changed because we did have neighborhoods. I did grow up with these kids and I don't know if we had block parties. But we knew each other we knew everybody, and I live in a very old, very transient Sparks' neighborhood. I don't know my neighbors, I don't know them because they come and go sometimes a month at a time…When I go to Portland, Oregon, I experience a neighborhood….It not only feels safe but it feels connected. I think it has to do with city planning."

He went on to say:

"If we have these enclaves of communities within a community, and neighbors are aware of the people who live there whatever their ages and the kids there would probably be sort of a protective nurturing feeling and attitude. I think that's what churches do now but I think that's what neighborhoods used to do. And in some cities that's what they still do. I don't see that in my neighborhood. If something were to happen to our house, I don't think anyone in the neighborhood would even care."

Also when the respondents were asked about what they would want to say to the Board of Commissioner's about active living and civic engagement with senior's one person said:

"I think if there was a way to find out where there were seniors who get cut off from other people and get information to them that would be very beneficial. I don't know how you'd do it these days other than by word of mouth. At the senior center, if we know information we know people that need it we go reach out."

In summary, several recommendations emerged from the group and include the following:

- Expand transportation options including the addition of evening hours for seniors who experience night blindness
- Investigate ways that city planning can encourage the reestablishment of neighborhood communities
- Investigate strategies for consolidating information about activities/volunteer opportunities and promote that information through multiple vehicles

Note:

For information about Senior Activities available through the City of Reno, go to the website:

http://reno.gov/index.aspx?page=315

Basic Needs Focus Group Report

August 29, 2013 1:00-2:30 pm

The focus group was designed to address the concerns that seniors have with meeting their basic needs – transportation, nutrition, and housing. There were five focus group participants; three had incomes below the poverty level and two were well educated with higher incomes. Of the five, two lived alone, one lived with her spouse, one lived with her son, and one was homeless.

Each was asked what type of support system was available to them in managing their day-to-day lives. The married participant indicated that her husband supported her financially and emotionally. Others mentioned friends, neighbors, and fellow church members. All indicated that God played a role in their lives and provided them with comfort. One, who is homeless, said she relied on services offered through the senior center such as AA.

The type of housing available to the participants varied considerably. Two mentioned they lived in homes that they owned, another lives in a mobile home, while the homeless person stays overnights at a church facility in a room with 30 other women. The final participant lived in a Section VIII apartment complex.

Considerable discussion was focused on Section VIII housing. The one living in housing provided under this program said that the apartments were not well cared for. Others complained about the long waiting lists necessary to get into the housing. One respondent who is currently homeless stated:

"I have been on the waiting list for Section VIII housing for a year and a half. I filled out all of the paper work. They say that they will call me, but they never call."

The participant currently living in Section VIII housing felt she was lucky. She had applied in 2004 for the program, and she had no difficulty in getting the housing. She noted that the situation was very different now.

The cost of housing and fear of future rate increases were top of mind for many of the participants. One, who is engaged in a senior advocate program, said that she worked with a client, who was eligible for services that could help her with medical services, but she was so afraid of a rent increase, so she did not apply for services.

"One of my clients was even terrified to ask for assistance. She had lived in her apartment for so long that she feared that if she went to the landlord and asked him to write down information (that she needed to complete the necessary paperwork) he would raise her rent. I kept telling her that they have assistance for her. That she could get her oxygen and a green box through the power company and they would take care of her. She was so terrified that the rent would be raised that she never went through with it."

When asked about other clients she worked with, she indicated that once they found out about the services they were very receptive to using them.

The mobile home owner was concerned about the rising cost of her lot rent. She said when she first secured the home she paid $400 per month for her lot rent. Currently, it is now $596.41, and it is expected to increase by another $20 in November. On top of her lot rent she is required to pay an additional $98 per month to cover the cost of sewer, water and garbage. These costs have only been added in the past few years; initially, she was not charged for the services separately since they were included in the lot rent.

Energy costs were a major factor for the low-income clients.

"I do get energy assistance, but they (the assistance payments) have gotten lower in the past two years. I've called (to renew the program), but you never get anybody….nobody…. She told me I would have to reapply by August 18th. She indicated that she would send me a letter. I sat and I waited…I waited. I asked at the senior center to get an application. She gave me one and told me to apply because I needed to be reassigned. You need to be recertified…I used to get Manufactured Home Section V for mobile home. That was about $100, but I no longer get it. When I asked I was told that I no longer qualify. I said I was at the poverty level and was told that Governor Sandoval had taken it out."

The two participants who owned their own homes indicated they had no problems, only having to pay for upkeep.

Getting enough food to meet their basic nutritional needs was a significant problem for the three participants who lived in poverty. One person reported that she only got one meal today and that was when she came to the senior center. She mentioned that they were excellent meals and were nutritionally balanced unlike other sites providing meals to the elderly.

Three persons were on food stamps but commented on how low the subsidy was.

"I get $26 dollars per month. When I asked about it, I was told that it was not supposed to cover all my cost for foods. I was told that I could stand in line at the food pantry, eat at the senior center, or I was entitled to commodities.

Another participant mentioned that she gets $42 dollar per month for herself and her disabled son.

"You live from day to day and you have to pick and choose what you are going to eat or not eat. Sometimes you get tired of eating the cheapest things out there. I get food at the senior center…it includes 3 lbs. of ground beef and 2 bags of sliced ham for the month. The Assistance League will also give you two bags of food if your income is under $1600 (per month)….I get my bread on Wednesday and it is enough to last the whole week"

The participant who is a senior advocate mentioned that you won't starve in Reno.

"Churches and other groups provide meals on Record Street. We Care are there Monday through Thursday. The Salvation Army provides bread bags daily. Churches provide meals on Saturday."

This same participant asked if people at or below poverty were eligible for Meals-On-Wheels. Others indicated that this service was only for persons who are home-bound. People who are eligible for the program must be home bound and must get slips from physicians to verify that they are eligible for the services. Meal cost is $2 dollars just like the senior center. One person indicated that she had heard that recipients stated that "this (the Meal-on-Wheels driver) was the only friendly face that they saw."

Transportation was the next topic introduced. Participants were asked how they get to where they need and want to go. The two participants with higher incomes indicated that they drove to where they wanted to go. Those participants at or below the poverty level indicated that they used public transportation or walked.

There was considerable passion expressed about the cost of senior transportation. Difference of opinions emerged about the actual cost of a single ride on City Bus and the length of time available to use the transfer passes. Some thought a single pass was as high as $2 per ride while others indicated that it was $.50. [After contacting RTC, it was learned that a one way trip pass for a senior is $1.00, but those with ACCESS passes could use the City Bus for $0.50 one way.]

"A regular senior is healthy enough to walk to a bus station (stop)…traveling by themselves, I give them a lot of credit, but they need a break on the fare….Healthy seniors are all on a fixed income. They need to give everybody who goes on the bus a break so the buses will not run empty. For every state I have been in, this is the highest cost for (senior) fare."

There was significant concern among those who regularly use public transportation that the price will increase. One participant noted that the majority of seniors at the (9th and Sutro) Senior Center use the bus to get there. An increase in expense for these seniors was viewed as a hardship. One participant who is on the RTC Transportation Advisory Committee said:

"I am the voice of Access….so I try to keep Access. They were going to raise the tickets for Access to $4.00 (for each one-way trip) and I told them that my seniors would have a problem. I brought them (the advisory committee) to the senior center. And I told the seniors to get there and tell them (RTC) what your problems with the buses……It's a problem because whose got $40.00 for five (two-way trips) every week, every week."

A side conversation occurred about the number of seniors who visit this Senior Center have problems with crossing streets, in fact, it was mentioned that a number of seniors visiting the center had been in accidents as they tried to cross the street. A participant familiar with RTC

plans and policies indicated that RTC have adopted strategies designed to cut down on these accidents such as increasing the amount of time available to cross on a walk sign.

"We are not getting any younger; we are getting older…and it hard for our legs to cross the street."

She continued saying that when Access is not running seniors can get cabs for the same price as the Access Van ($3.00). There are some problems she stated:

"Sometimes they (cabs) get there and sometimes they don't."

Another problem reported was that the van and cab drivers are supposed to provide "door-to-door" service rather than "curb-to-curb" service to assure that frail elders can navigate the distance from their home to the cab or van. Although drivers have been notified that they are to be escorts from the door to the vehicle, not all drivers provide this service putting frail elders at risk of falls and injury.

Next participants were asked about the quality of the service. Most of the discussion that ensued focused on the drivers.

"I have ridden the City Bus for 15 years, I find the drivers unkempt, unfriendly, and rude. I know all of the bus drivers on my route and there are only five who are friendly."

Other participants asked her if she had filed a complaint, she answered:

"I have fallen three times outside of the station, and I have filed complaints. I have heard nada, not a single word."

Other participants indicated that they have had a similar experience.

In closing, participants were asked about important issues that need to be addressed in the future. The following is a list of concerns raised by the participants:

- Include dental coverage for those seniors who are on Medicaid. There is nothing currently available.
- Increase funding for Section VIII and other senior housing since there are too many seniors living on the street.
- Expand funding for Meals-on-Wheels and increase what is included in each meal to assure that the home bound can have more than one meal a day. For example, include more bread and butter so they can have toast for breakfast.
- Make public transportation service more available to seniors at a cost they can afford.

Notes:
Transportation: According to RTC (2013), there is no bus service to Cold Springs, Spanish Springs, Hidden Valley or the Washoe Valley areas.

Food:

Best and Worst States for Senior Hunger. Nevada ranks as the 4th worst.

nfesh.org@mail185.wdc02.mcdlv.net, (2013)

Top Ten Worst

Rank	State	Percent
1	AR	24.23
2	MS	20.49
3	AL	20.34
4	NV	18.8
5	TN	18.79
6	LA	18.76
7	TX	18.35
8	NM	18.05
9	GA	17.52
10	SC	17.38

Top Ten Best

Rank	State	Percent
1	VA	8.41
2	MN	8.59
3	ND	9.3
4	NH	9.98
5	DE	10.14
6	VT	10.77
7	CO	10.87
8	ID	10.87
9	WI	11.01
10	NE	11.17

Housing:

In 2006 a ten-year development plan was created to end homelessness. A housing gap analysis was done. These are some of the figures as to why this was a priority.

Fig. 3 Continuum of Care Housing Gaps Analysis, 2004

		2004 Inventory	Unmet Need/Gap
Beds	**Individuals**		
	Emergency Shelter	**167**	**178**
	Transitional Housing	**289**	**377**
	Permanent Supportive Housing	**343**	**436**
	Total	**799**	**991**
Beds	**Persons in Families with Children**		
	Emergency Shelter	**154**	**90**
	Transitional Housing	**102**	**117**
	Permanent Supportive Housing	**28**	**606**
	Total	**367**	**813**

Source: Reno Area Alliance for the Homeless, Exhibit 1, 2005.

Caregiving Overview

In August, two focus groups were convened. One addressed the topic of Caregiving. The second focused on Home and Community-Based Care Services. As the second focus group progressed, it became clear that the group learned of these services as a function of their former caregiving responsibilities. Therefore, the findings of both groups are similar.

There were similarities as well as differences in the two groups. The first group was actively involved in providing direct care to their family members while in the second group the care recipients had all provided care in the past. In the first group, participants were struggling with finances and were striving to pay for services. The second group was more highly educated, and two of the participants had backgrounds in medicine. However, finding available home and community-based care services appeared to be as much of a problem for them as the first group.

Several shared themes emerged from the group:

- Since the caregiving experiencing was financially draining for all participants, core recommendations from both groups were:
    - Investigate and advocate for financial assistance for low- and moderate-income families who provide care in their homes; research what other states/counties are doing to help caregivers.
- The desire for expanded respite care was also a major priority, with participants indicating that caregiving is a 24 hour job:
    - Consolidate information on respite care facilities and promote it though a range of vehicles.
    - Develop a co-op of caregivers who can provide short term respite care.
    - Advocate for expanded subsidies for respite care. Investigate what other states/counties are doing to provide financial support for caregivers.
    - Advocate for the expansion of Medicare coverage for home and community-based care services to enable more seniors to remain in their own homes as they age.
    - Consolidate information about the various grants available to finance respite care.
- Having improved and accessible caregiving educational services was important to participants; they indicated, however, that they knew programs currently existed but due to the burden of their caregiving responsibilities they were unable to attend classes:
    - Investigate what topics caregiver's want information on; understand the best vehicles for providing education/training; launch a range of educational modes to meet the needs of a broad range of caregivers.
    - Create more accessible Information and Referral services; publicize the availability of I and R services.
    - Offer home safety checks for caregivers managing patients with dementia.

- Many of the participants were dealing with relatives who had dementia or Alzheimer's Disease:
    - Advocate for more research on the origins of, treatments for, and prevention of dementia and Alzheimer's disease.

The following pages detail the discussions and concerns of caregivers in Washoe County.

Caregiver Focus Group Report

August 16, 2013 10:00-12:00 pm

Five caregivers attended the focus group; all were over 60 years of age. All had at least five years of caregiving experience, with a majority having between 10 and 20 years of experience. All but one caregiver was providing support to a parent; one supported her husband. All but one of the care recipients had dementia or Alzheimer's disease. There was one male and four female participants. One is a long-distance caregiver and four had the care-recipient living in their home full-time.

Participants were initially asked what their greatest concern as a caregiver was. Two mentioned hygiene, in particular toileting. Others mention just having personal time when they did not have caregiving responsibilities. One participant specifically stated when asked about their greatest concern:

> *"…biggest concern for me is more of having a life, all my siblings live here but for whatever reason, they visit but they can't take care of mom…so just having time off…when you wake up a couple times a night and you have to change a diaper….. You have all these things you need to do and you have to work in the morning to make your living..... and just having more time available where you could have weekends away, where you could be alone in your own house, I am never alone in my own house. Ever."*

Several mentioned the demands of providing care during the night. One mentioned that every night she was up for four to five hours. She mentioned that on average she only got a total of 4 hours of sleep during a given day. Most agreed that getting sleep was a significant problem. Some mentioned that they had not had a full day off to themselves in years.

Some mentioned the consuming aspects of caregiving. One mentioned that providing care to an adult parent with dementia was like supervising a child, explaining:

> *"It's like having a very small child… you can never leave them alone….I had to put locks on the front doors so that she doesn't answer the door when I am outside gardening, you know…to a complete stranger, you know who could muscle their way in the house. So you know respite is very important, and I see there are gaps in the respite service that is available."*

They cannot be left alone for even a minute. One woman mentioned that her husband wanders and she has to be constantly diligent so that he doesn't get lost. Another mentioned that she has had to put locks on the thermostat and doors. Her mother will turn on the heat when the temperature is very hot outside. She will also open the main house door and leave it open when the air condition is on. She also had a tendency to wander. The demands are unrelenting.

Another issue frequently mentioned as a top concern was managing the dynamics of family relationships. Family members who are not providing direct care are generally unaware of the full-time demands on the family caregiver, one explaining:

"…you get isolated, and they (my family) just don't understand the pressure…. no, no they just don't get it."

One person specifically mentioned that it appeared that the family members were avoiding the recognition that the care recipient was declining, stating:

"For some reason they don't want to admit to what this other person is doing (talking about the care recipient), and they don't want to do it, and I don't know…."

Another participant adding:

"They have a lower degree of (the ability to) confront, okay? And they can't confront it, because when I talk to my sister, she says," "I just can't handle all of this,"" and basically what I am hearing is she can't even handle to hear about it ."

Further, most of their family members were unwilling to provide hands-on support on a regular basis whether because they were working or had other demands on their time. If the care recipient were hospitalized, they would come and stay at the hospital, but were unavailable when the person was released to the home environment.

Funding caregiving was also a concern for families. Some family members had the impression that it would be less of a family financial commitment to place their parent in a nursing home or assisted living facility, one individual explaining:

"Strangely enough, my family doesn't understand the incredible cost it would be (to put her in a home)…they really think that if they go and talk to these other people (mediators) we will cut out the (agency) and cut out XXXX (name of participant) um, you know that it is somehow going to be cheaper…and no its $9-12,000 for out of home care…they want her placed in a home, and she's happy with me. They don't even get that it's cheaper. My sister, although retired, won't provide any of the help."

One family had gone so far as to demand they go to mediation to place their mother in a "home," but the caretaker reported that her mom was quite happy at home, and that although still expensive, it is cheaper to keep her in her residence.

Only two participants had worked while serving as caregivers. One had worked, but had retired to help manage her caregiving responsibilities. One was still working, although they said:

"Thank God for the (agency), or I couldn't continue working..."

She indicated that while her employer was flexible and allowed release time when her mother was ill, she believes that she was passed over for a promotion due to her caregiving responsibilities. She reported that her employers did not always differentiate the demands of a working parent from those of a family caregiver, stating:

> *"It's a totally different thing to say your child is sick than to say my mom is sick, it really is, it really is different…..people have a hard time understanding that an emergency of an aging person is different than an emergency of other people….you go and take your mom to the emergency room, you have one of your siblings come and you go back and you are at a meeting in a half hour, people look at you like you are bizarre and what's wrong with you? …"*

This passage explains how when her mother was hospitalized, she took time off to take her mother to the hospital and waited until her sister was available to stay with their mother. She then returned to work for a 2:00 pm meeting that she believed was important for her to attend. Her employer did not understand why she was not at the hospital with her mother.

Next, caregivers were asked to discuss the financial impact of caregiving. One mentioned that it was:

> *"Catastrophic….all I contribute are all the groceries, you know with a mortgage payment and car expenses," (Discussing the $2000 she lives off of a month with her care recipient and all she can contribute is money for groceries).*

The others were very reluctant to discuss the financial and physical impacts of caregivers. When asked about the emotional impact, all admitted that they suffered from depression and isolation. They had lost connections with family and friends because their caregiving responsibilities were totally consuming. One indicated that the family friction over caregiving issues had resulted in a form of alienation.

Another major concern was the deficiency in respite care services. Those who used the (agency) were satisfied with the quality of the care as well as the cost. Some had learned of grants available that helped them afford the services two to three afternoons a week. Another participant had just learned that a facility offer's persons up to five days of respite care if they had a grant. The charge for the service was $70 per 24 hours of care if they had the grant. A different facility was mentioned as another facility that provided care on Saturdays and on most holidays with the exception of Christmas, as one participant stated, "that's another thing, none of us get holidays." Sharing information on these services was a benefit to most participants since they were unaware that these respite services were available. Other respite services did not receive high ratings. Most mentioned the cost as a barrier. They noted that the cost was $21-$23 per hour with a minimum of four hours of respite care. One indicated that these costs were

"ruinously expensive." All mentioned that overnight respite services were the hardest to get, although often the most needed.

One participant mentioned about states providing financial support to caregivers:

"….the Alzheimer's Association was taking a thing to the legislature, … I went and talked about it because I know there are other states who provide funding for relatives who care for their aging parents and we've never seen this here….but that's … critical because you know even for me with my mom having assets my family doesn't seem to understand, that they somehow think that I am getting paid."

This is not done in Nevada. She noted that these states had vision. Most participants resonated with her when she said:

"If caregivers like us suffer burnout, the state is going to have to pick up the cost of the care."

Two of the participants mentioned that they worried about who would fill their shoes if they no longer were able to provide care. One woman had fallen in the past year and was unable to support her husband for a few days. She became worried about what to do if she were unable to provide care for an extended period of time, explaining:

"Earlier this summer…I fell and … injured my back...I was maybe down for a day or two, but it was an eye opening experience because if I had broken something and was unable to care for him, he could not function, he can't make coffee..."

Another woman had foot surgery. She was an invalid and could hardly care for herself. None of her family was willing to provide care to her mother while she convalesced. Trying to provide care to her mother post-surgery delayed her recovery and left her with carpel tunnel syndrome.

Three participants had experience with their parent being placed in a skilled nursing facility. All were very dissatisfied by the quality of care their parent had received. One said his father had been placed in the facility following a bout with pneumonia. One night his father called needing help and said that no one had come to his aid. The son arrived to find is father half out of bed with his catheter out and the bed soaked with urine. The son wanted to take his father home, but was told he could not be released. He secured a lawyer through the Senior Law Project who advocated for his release. The son believed that the facility would not release his father because they wanted to collect for the full ninety days paid for by Medicare. He went on to say that he considered this as a form of Medicare fraud.

Another participant indicated that her mother had broken her pelvis and was transferred from the hospital to a nursing facility. She complained that during the first four hours of her mother's care in the facility she was not provided any pain medication and the staff would not allow her to administer her mother's pain medication. Further, she was not fed during her entire four-hour

stay. She immediately contacted the mother's primary care physician and was able to get the mother released to her care.

One person mentioned that she had placed her mom in a skilled nursing home facility; however, the facility would call her nearly every night to come there and help calm down her mother who experienced the "sun down" syndrome-

"You have to go down there to calm them down, so they don't fall or they don't get restrained or chemically restrained because all of those things (changes) are very difficult for the aged, they don't respond well."

She finally took her mother home with her, because it was much easier to take care of her mother at home.

An overriding complaint that the participants had was related to home health resources. All were frustrated by the constant turnover among the CNAs who provided the bulk of in-home services. This caused multiple problems. First the care recipients were not comfortable with them providing personal care, like bathing, etc. They were embarrassed. They found it extremely difficult to adjust to new staff coming in nearly every week. The caregivers were frustrated by having to constantly "educate" the CNAs about how to manage the care in their home, such as where the medications were stored, one caregiver stating, "they were in the way actually," and another-

"We ran into the same problems just trying to bring someone in to help with hygiene, it was a stranger all the time coming in, and it was very, very difficult… staff changes all the time, it is very difficult, we just did this last year, and took him out of the home setting and got him a 24/7 caretaker, then I had to kind of watch over the caretaker, she wasn't getting the meds right and there were other issues and that had its complications, I discovered that, …I had to be a full-time manager of the caretakers, and that is almost harder."

Further, they felt that the CNAs acted as if they were in the home to oversee the services provided by the family caregiver. The caregivers felt that the services that the CNAs provided were redundant of the care they had already provided, and the CNA's were unable or unwilling to provide the much needed services that the caregivers wanted. They felt like having the CNAs there was a waste of their time, was not a relief to them, and was a waste of Medicare monies. One particularly mentioned that Medicare had provided them with a speech therapist when it was not warranted. This was highly expensive to Medicare and not needed by them. Also it was stated that many of the home health services have guidelines that,

"It's like when you contract in-home care services, they have parameters set, where ..., the person being cared for has to be able to do his own medications and it just doesn't work, because, you know, here we are and our people can't do their own medications, they, may or

may not ask to get up to go to the bathroom, you know assistance, and then we are in a gap of care here, because they are unable (perform this type of self-care)."

Next, participants were asked if they had formal caregiving training or participated in caregiver support groups. While they were aware of these services, all indicated that they had not used them. Once again, the demands of full-time caregiving was so consuming that they did not have the time or energy to participate. Two participants noted that they would need "Mom" or "Dad" care to make it possible for them to participate. In general, they indicated that access to information was difficult. They felt that they needed a single-point of entry access. Two mentioned that they thought that the 2-1-1was supposed to serve that purpose, but they believed that it had been defunded. When they were asked if they were familiar with the Washoe County Information and Referral Service, they indicated that they were not aware of it. They commented that they needed more information about Washoe County Senior Services, particularly about the proposed cuts outlined in the news. They wanted an update on these cuts, but also more information about what services were available to them through WCSS.

They were asked what services/resources they would need to manage the stresses of caregiving. Numerous suggestions were made, including the following:

- Developing a pamphlet or resource guide for families focused on the comparative costs of care.
- Washoe County could educate Senators and Congressional Representative on the needs of caregivers and the need for more research and demonstration projects.
- Increasing funding for research on Alzheimer's disease and dementia.
- Developing a co-op of caregivers who are willing to provide temporary relief.
- Consolidate information about the various grants available to finance respite care.
- Consolidate information about local respite resources.
- Investigate legislation that provides financial support for family caregivers.
- Create PSA's explaining the toll caregiving places on family and in-home caregivers.
- Increase public information about what Washoe County Senior Services does and the resources they have available.
- Investigate whether Washoe County Senior Centers can provide supervision of care recipients.
- Count the number of caregivers in Washoe County.
- Investigate whether County could match funding provided at the (agency) so that more relief time could be made available.
- Investigate whether an in-home care provider could educate caregivers on more difficult tasks such as lifting in general with focus on how to handle a care recipient when they are wet and slippery from a bath.
- On a federal level having more funds for Alzheimer's research. One participate explained he didn't understand why more money was spend on HIV funding than Alzheimer's

funding when there seems to be this growing need for more money for Alzheimer's, (Graphs at the end of report, Alzheimer's Association, 2013).

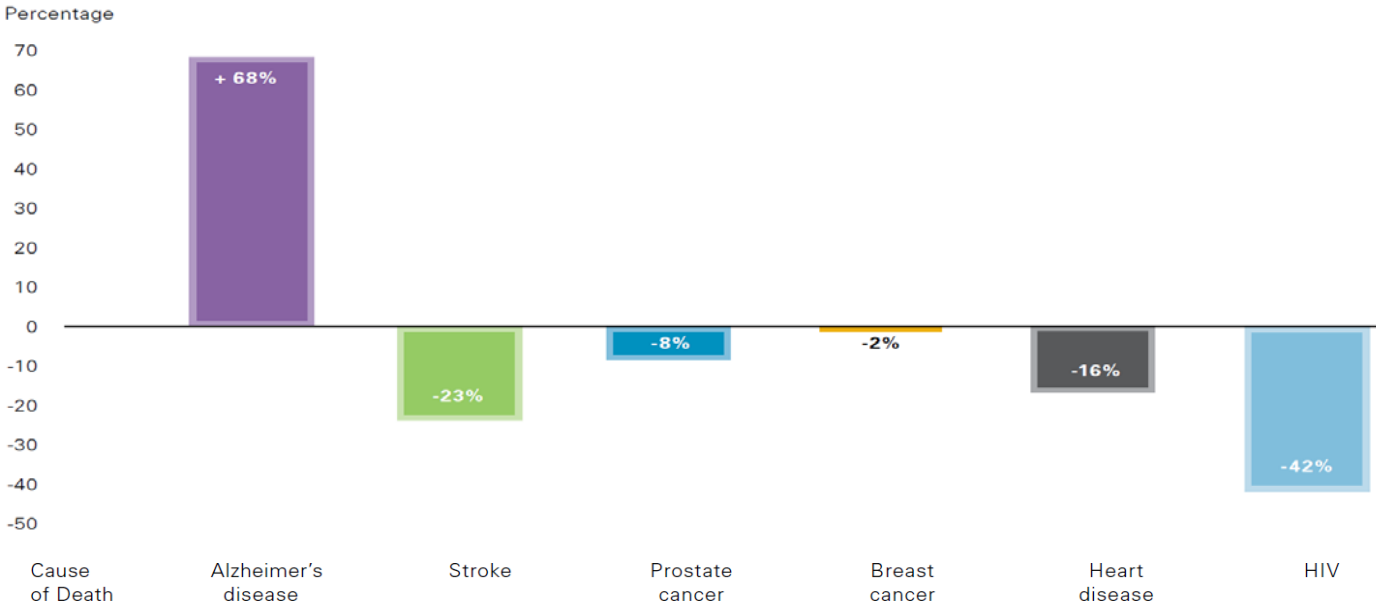
In closing, the caregivers indicate that there are actually good things about caregiving. They are all givers and feel rewarded by being able to help their care recipient. They can also share the lucid moments and happy times with the care recipient.

Notes:

Graphs

Nationally, the percentage changes in selected causes of death-

FIGURE 5 | PERCENTAGE CHANGES IN SELECTED CAUSES OF DEATH (ALL AGES) BETWEEN 2000 AND 2010



State of Nevada, the projections of total numbers age 65+ with Alzheimer's

TABLE 2 | PROJECTIONS OF TOTAL NUMBERS OF AMERICANS AGE 65 AND OLDER WITH ALZHEIMER'S, BY STATE

	Projected Total Numbers (in 1,000s) with Alzheimer's			Percentage Change in Alzheimer's (Compared with 2000)	
State	2000	2010	2025	2010	2025
Nevada	21.0	29.0	42.0	38	100

Reference

Alzheimer's Association, (2013). 2013 Alzheimer's Disease Facts and Figures

Home and Community-Based/Long-Term Care Focus Group Report

August 29, 2013 at 3:00-4:30 PM

Three individuals attended this focus group, all were former caregivers. They all had personal and professional knowledge of home and community-based long-term care services.

There were two females and one male participating in the focus group. Two had provided support for their mothers and one for her husband. In all instances, care was provided in the caretaker's home. Two participants are nurses. Two are still working in community-based senior services, and one is retired but does volunteer work for a community-based senior service organization.

Participants were first asked about the home and community-based care services that they have used personally. One mentioned that Renown had sent out a team to help with her mom's care. Another stated she had tried to use a CNA, physical therapist and speech therapist that Medicare would cover, but she felt that the individuals hired by Medicare were not helpful, so she ended up hiring, out-of-pocket, a private nurse along with speech and physical therapists. She also mentioned having someone live-in to take care of her husband, but then felt the individual was not trustworthy:

"…It is very, very hard to find trust (trustworthy providers) that you can depend on…." (Referring to having someone come in the home to help take care of her husband).

So she ended that service.

Another mentioned having someone come out and bathe his mother, along with cleaning her room weekly, also stating he had a,

"…Home care nurse to help us with her diabetes, to help regulate that."

Another participant used the Alzheimer's Association to help find and use resources for the care-recipient. Two also mentioned using Hospice, where one participant said:

"Hospice, they were wonderful."

One participant specifically indicated that her greatest concern was coordinating appropriate care:

"Regular people come and take care of my husband, and it's not working out, wife needs a break so, so I go out two hours, my husband was still in the bed, I don't go for that type of stuff, so I used Medicare Services, is that what they are called? Medicare sends you an RN and then Medicare sends you a lady to give him a bath, but it's not delightful and they do not do the whole thing, like if you have a wound on your hand, you better have everything ready, they aren't there

to help that much…. The physical therapist, I finally found a good one, speech therapist I found a good one, but however…it takes so long to find the one that fits my husband and I found out that Medicare assigned it to you, you have to make so many excuses to get one out….well I didn't like this speech pathologist I have to research it and so it took me this long, I find another one…but Medicare don't approve that, so it's coming out of your pocket."

Another participant said her mother's insurance was adequate and so she was able to get proper help for their mother, stating:

"I didn't really have any challenges. They were there when they said they would be there, they did what they said they were going to, uh, you know, I guess I was really lucky, I got a great company that was involved in taking care of her."

The last participant said it was a mixed blessing being able to care for his mother, because he lost his job the day before she moved in with them. The participant discussed his frustration with caring for his mother, not knowing all the resources available, and the economic toll it took on their family, explaining:

"….we blew through my severance, my 401k; everything else…my mom was a burden in terms of finances." (Referring to the time spent home caregiving).

Some mentioned the time-consuming aspects of caregiving and finding home-based services to use, where one person discussed having to put their head in a pillow to scream in order to relieve stress,

"I didn't know how to seek them out." (Referring to respite services.).

Also while being a caregiver, you have to be constantly vigilant with the care-recipient because they may wander or fall. One respondent suggested that:

"That would be something you would want, a safety team to come in and say those rugs shouldn't be there because they are a trip factor or this or that….a safety team might be real good to talk to people…"(A suggestion to improve services/home caregiving)."

Safety was a big concern for these individuals when they were caregivers. One participant told a story where he pulled up to his house, to find his mom coming through the gate to meet a family member, but there was no family member to meet her.

The emotional impact of caregiving was also examined. Some participants felt they were not prepared for the challenge that was about to be part of their lives, many felt mixed emotions. Care recipients also tended to be on "emotional rollercoasters" themselves, having bouts of behaving like a child, mixed with depression. One participant mention the dilemma of answering the same questions 30 times in a row, or not being able to even raise his voice because he was worried he would scare his mother. One individual explained she knew she could not take it out

on her mother so she would take it out on something like a chair at home. The participants also stated they had no time during these periods of their life to use community resources for emotional support like caregiver support groups.

The participants were asked about the financial impact of using home-based services. One individual explained that if she had not had the money and resources that she did have, her husband would have suffered:

"If I didn't have those types of money, he would have been a vegetable…" (Referring to the fact that if she did had not saved up money her husband would not get the proper home-based services he needed).

In order to have these resources she had to cash in their retirement completely and sell one of their homes.

Another individual explained that:

"*We looked into extended care, but we couldn't afford it, so the best thing is we brought her to live with* us."

While still another person stated that:

"….I just had to pay it…." (Referring to cost of home-based caregiving services).

One individual went on to explain that the retirement that she had visualized did not exist and because of the financial burden of care-taking she had to go back to work after her mother passed on, and there is now no clear time in the future to when she will be able to stop working and retire. Also, they said they have wanted a safe, community-based place they could put their mothers, but that they had trouble finding one that was affordable.

When asked about the home-based long-term community services that they knew about before they had to care-take, one respondent said:

"Having worked in medicine all my life, I was really surprised at what I didn't know was out there….when she had about six months left to live I found out about the RSVP program but unfortunately they didn't have volunteers that went out to Washoe Valley." (In response to what community services they knew about before having to deal with caregiving).

While a second individual explained:

"We started at ground zero….. What sort of failing's health wise were we needing to deal with; it was macular degeneration, it was diabetes, it was senior leukemia, so you try to cover all the bases, and certainly short-term memory loss." (In response to what community services they knew about before having to deal with caregiving).

Finding respite care also seemed to be a concern when these individuals were looking at home-based care for their family members. Besides access to services, cost was a factor that limited availability of resources. The quality of care was mentioned also, where one individual felt the CNA's that was sent in by Medicare were, "*Inexperienced."* Also two of the three members cited having to use their spouse for respite care just to get a break, where one said:

"If my husband couldn't help me to take care of my mom I didn't get a break."

Access to available services was a barrier that was mentioned in the group. Where one individual explained:

"I knew how to seek them out; they just wouldn't come to where we were at." (Referring to respite services).

Not just geographic restraints but also time restraints were placed on home-based services, for example one participant stated:

"Medicare only gives you so many days or whatever…" (Referring to challenges in getting a physical therapist).

Professionally speaking, the participants discussed other barriers as well. Such as age barriers or a minimum age to getting certain resources. One person explained there are income barriers as well, such as a family having too much income, but this becomes a problem if the person just has a little too much income to qualify but not enough income to actually take care of and pay for services. For example, one care-taker said that her care-recipient needed a piece of equipment for his medical treatment, but she was told she could not borrow one because she made too much money, forcing her to buy an expensive piece of machinery.

Yet another individual mentioned the paperwork burden. When her care-recipient had cancer, she had to do so much paperwork to get help paying for the cancer medication that was very expensive. That everything had to be justified, and there was too many, *"volumes and layers to access,"* and that this process became defeating. With all the paperwork, she noted that an individual has to plan very far ahead.

When asked about long-term living facilities and whether they had looked into those, two of them mentioned they had but as one person explained the facility was, *"…a chaotic mess….with mattresses on the floor….so the people would not roll out."* Another said he pulled his mother out of a facility because of the standards of care and the mother was not happy there and she refused to eat. The third person explained, *"I wouldn't put one foot in one."* Going on to explain that it upsets her that individuals are restrained in nursing homes. Plus, the participants all agreed that long-term care facilities are financial drains even more so than home-based or community care.

When asked what need to be done to address their home and community-based care concern, they wanted:

- Operate a home safety program that alerts individuals/families to potential threats in their homes.
- Investigate/Advocate for financial assistance for low- and moderate-income families who provide care in their homes; research what others states/counties are doing to provide financial support for caregivers.
- Investigate what topics caregivers want information on; understand the best vehicles for providing training; and launch a range of education modes for training caregivers.
- Advocate for and expand subsidies for respite care to allow caregivers to get a break from their overwhelming responsibilities.
- Improve access to home and community-care services for persons living in more rural areas of the county, such as Washoe Valley.
- Advocate for the expansion of Medicare coverage for home and community-based care to enable more seniors to remain in their own homes as they age.
- Create more accessible information and referral programs that are user friendly for caregivers.
- Create standards for measuring/improving the quality of care provided by home care workers.

In closing, the Home and Community-Based Long-term participants explained that they had no regrets and loved the ones they had taken care of. That their care-recipients were happier at home, and they managed to find ways to make it work for them.

Notes:

Table 1. Planning and policy framework for CHBC

Category	Items to be addressed
Nature of the programme	Purpose, goals and objectives of CHBC Target population Location Time frame
Eligibility criteria	Age Disease category Degree of disability Relationship of caregivers Knowledge of diagnosis Number of CHBC hours Ability to pay Degree of family support Provision of physical and emotional care Provision of housekeeping duties General state of family and home
Eligibility assessment	Assessment tool (universal or contextual) Who will be the assessor? Measurement of the level and type of care
Benefits	Cash allowance, service provision or combination Maximum and minimum benefits Waiver system Medicines and supplies Food provision Transport Respite and day care services Counselling Basic nursing care Assistance with housework
Programme operation	Government-run or joint operation Responsibility for service delivery Care planning Education Quality assurance
Financing	Funded through general taxation Cost sharing Funding by other organizations Cost containment
Coverage	Percentage of the population covered Locations Disease categories and target populations Levels of disability
Cost	Cost of services Hourly cost Ratio of paid to unpaid workers Education Medicines and supplies Transport Food supplements

This chart shows the framework necessary in a systematic approach for policy-makers to use when developing policies or guidelines for Home and Community-based care, (*WHO.* Long-term care laws in five developed countries: a review. *Geneva, World Health Organization, 2000 (document WHO/NMH/CCL/00.2)*.

Economic Security and Work Force Participation Focus Group

October 7, 2013 1:30-3:00 PM

Two women each in their sixties participated in the focus group. One woman also brought her husband who has Alzheimer's, but he did not participate. This woman is her husband's caregiver and cannot work outside of the home. However, she teaches art classes to one client in her home. The other participant is currently seeking part-time work and recently was forced to retire explaining:

"I'm actually looking for a part-time job for now, and it hasn't been easy, because I got involuntarily retired. My neighbor behind me, she's a caregiver. She wanted to find another job, and she couldn't find anything. She wanted to volunteer as a caregiver, but there were so many blood tests and questions, it made it impossible, and she is a nurse…. I didn't expect to retire, and I thought I was going to work till I was 70, but that didn't happen."

Both participants are in the process of buying their homes. One woman stated:

"We don't own it, we are paying on it. We are going to run out of retirement (funds) shortly. My kids have offered to step in, but that's not really ideal. I don't want to be a burden to them."

Next, the participants were asked about their sources of income. The single woman said:

"I'm living off of Social Security right now. I don't know how long that's going to go."

The couple stated that besides their retirement, Social Security and teaching art classes, one of their children live with them:

"I have one daughter that lives with me. (When asked if she offers financial support, the answer was :) Ya, sometimes."

The people were asked whether their limited resources keep them from doing the activities they would like to do. They agreed that it does. One commented:

"We don't plan trips…. We have more bills than money, so we are paying the rent (mortgage) every month."

Next, the participants were asked what if any steps they had taken to better manage their financial situation. The single woman stated:

"It would be nice to refinance….When I bought my house 15 years ago; I paid way more money than what it is selling for now. So the bank would offer a refi … The cost to do whatever it's called the ratio isn't enough for them to do it. They won't do it, because I still owe more on it than what the house next door is selling for."

The couple said:

"I was able to refinance and that made a huge difference in the overall expenses."

When asked if they were eligible for any low-income assistance such as food stamps, the couple explained:

"Just too much Social Security, but really it's not enough, otherwise we wouldn't be in the red."

Next, the participants were asked about their medical expenses, and how their lives are impacted by them. The couple stated:

"That's why we'll run out of money …. Because of medical (bills and) because of the hospitalizations, and the deductible. They just keep piling up. Tremendous drain of what would normally be considered your retirement. There's so many glitches in the hospital system that you have to check and I'm saying to myself how many times do I have to solve this problem….It's a challenge with the technology and the billing. It used to be you'd go to the doctor and pay him and that was it….(now) Always on the phone, always on hold … I realized this is the new norm, and I can't get upset about it….. It gets a little overwhelming at times."

The couple went on to discuss their financial burden:

"If I did need help, then there needs to be an easier way for affordable help, and I'm not sure because that would just come and wipe out everything, and then the burden on my children and I don't think that's fair because they have their own life and expenses and bills. I feel a little vulnerable you know. I'm looking for ways to utilize what we have and deal with it."

The woman continued to discuss the impact of medical expenses on her life by saying:

"Then there's the dentist, you don't have any insurance. We don't have much coverage for that so that's another huge drain. I've kind of put myself on the backburner for medical. But I also know that I have to take care of myself, so we exercise, we walk, and eat right…. I'm eligible to collect it from my former employer (medical Insurance) but I can't get through."

The other female participant also explained that while she gets by with her standard monthly bills, if an emergency or something were to come up, it would be very difficult for her to pay for it:

"I'd be in a pickle if my car didn't run. If I had to get another car, forget it. I would be better on a bicycle. I can't make a car payment."

One woman discussed seniors in Washoe County in general and where she sees a major problem for a percentage of the population:

"All these seniors need support. A lot of them live by themselves, they don't have family that's calling them on a regular basis, and so you are extremely vulnerable. You could find things which would help to make you not feel so isolated….Maybe have like a buddy system where they could call each other. Pair seniors up with other seniors."

She also discussed how she sees the job market in general, not just with seniors but with the whole population:

"I have two highly educated daughters, and they can't get jobs. One of them has a master's degree and she works at UNR part time. The 2nd daughter she was working for a lawyer and he had to close his shop for financial reasons. And then she was working with H&R Block."

When the other participant was asked about how they see the current labor force she explained:

"I worked for 23 years, (actually) longer 38 years consecutively. So I haven't had to look for work. I haven't had an interview recently, but when I do they are going to notice the first thing…. My hearing aid."

She worries that one of her barriers to getting work will be her apparent age; that her grey hair and hearing aid will be judged over her merit and qualifications.

The couple went on to explain the hardships of caregiving, the issues facing many seniors, and how she would afford help in the future if she were to need it for her husband with Alzheimer's.

"We are at a stage where it is still manageable. When he was hospitalized, I couldn't do anything. I had cataract surgery, and I couldn't drive or anything. That's the other thing for seniors, if you don't have a way to get where you are going then you are kind of stuck. Then you need someone to care for (you). That's kind of my concern coming down the road. Things changed (and) I would need the kind of assistance I couldn't afford."

She said about respite care:

"There's really a need for people, support for people… maybe spending a couple of hours so they can go out ….volunteer services that would be really helpful."

She also discussed the problems with accessing information about services, especially for caregivers:

"…Flyers to pick up for topics. It doesn't even have to be specifically a big flyer. The doctors aren't even aware about the help that is available…People need to come and make sure that they can get food. They need to be able to drive for themselves or to get help. I found that when he got home from the hospital and needed care, I couldn't go out and do that. People with Alzheimer do not do well in a hospital. You go there for a physical ailment, and then there's a situation that they do not know how to treat. Then, it was up to me to stay there and be the third

eye…. Even though they did the best job they could, it wasn't enough. So if I wasn't there, there would have been a lot more issues for everybody. It was probably the least safe place for falling …. It wasn't right…. It wasn't right. I had to be on it all the time…. The situation was horrible with hallucinating and fall risks. The thought of having to go back into a situation like that is terrifying for us. I want to be able to go to one place to pick up the thing I need to see. Right now I can go around and struggle getting what I need."

Recommendations made by the group include:

- Explore options for volunteer-supported respite care programs.
- Organize information about senior services and make it available through a one-stop system.
- Consider organizing senior-to-senior buddy programs to reduce feelings of isolation.
- Expanding support programs for seniors returning to work after long-term unemployment.

Notes:

Economic Security for Seniors: Fact Sheet

Retirement is not "golden" for all older adults. Over 23 million Americans aged 60+ are economically insecure—living at or below 250% of the federal poverty level (FPL) ($27,925 per year for a single person). These older adults struggle each day with rising housing and health care bills, inadequate nutrition, and lack of access to transportation, diminished savings, and job loss. For older adults who are above the poverty level, one major adverse life event can change today's realities into tomorrow's troubles.

Poverty Measures

- Social Security is a lifeline for older adults, providing at least 90% of income to more than one-third of America's seniors. If it weren't for Social Security, nearly half of Americans over 65 would live below the federal poverty level (FPL). (Center on Budget and Policy Priorities)
- The FPL does not account for the rising cost of living seniors experience as they age, which can include illness, loss of a spouse, or care for a disabled spouse, adult dependent child, or grandchildren.
- More accurate measures of economic wellbeing—including Wider Opportunities for Women's Elder Economic Security Standard™ Index and the Institute on Assets and Social Policy's Senior Financial Stability Index—show millions of older adults struggling to meet their monthly expenses, even though they're not considered "poor" because they live above the FPL, which is $11,170 for a single elder.

Income & Employment

- Many seniors rely on fixed incomes, receiving on average $1,234 in Social Security benefits, $516.90 in Supplemental Security Income each month. (Social Security Administration)
- Older women fare worse than men, with 60% unable to cover their basic, daily expenses compared to 41% of men. (Wider Opportunities for Women)
- Weekly earnings vary by age and gender. Men aged 55-64 have the highest average weekly earnings at $1,015, while women earn $760. The average weekly earnings for men 65 years and older is $780, while women earn $661. (Bureau of Labor Statistics)
- In July 2012, 30.2 million Americans aged 55+ were employed, and around 2 million were actively seeking work. The unemployment rate for mature workers in this age group is 6.2%. The average duration of looking for employment is 51.4 weeks, just a few weeks shy of a year for this age group. (Bureau of Labor Statistics)
- Workers aged 62 and older are the least likely of any other age group to regain employment after a period of unemployment. Many seniors simply stop looking for work and choose to draw on their Social Security benefits instead. In fact, as the unemployment rate rose in 2009 so did the Social Security retirement claims. (Urban Institute)

Debt & Savings

- One-third of senior households has no money left over each month or is in debt after meeting essential expenses. (Institute on Assets and Social Policy)
- In 2012, the average credit card debt among adults aged 65+ was $9,283. (Demos)
- 14% of adults aged 65+ face retirement with negative net worth, contributing to a rise in bankruptcies that has grown at the fastest pace ever due to high credit card debt and debts against their home. (Aging and Bankruptcy, U.S. Courts)

Health & Nutrition

- Approximately 14.8% of U.S. households with an elderly member were food insecure in 2010. (National Foundation to End Senior Hunger)
- Only one-third of eligible older adults (age 60+) are enrolled in the Supplemental Nutrition Assistance Program (formerly Food Stamps).
- People of color are more likely to have a chronic disease and, therefore, greater healthcare needs; however, due to a history of disproportionately lower wages, seniors of color typically have fewer resources to cover their expenses. (Kaiser Family Foundation)

Housing

- As of December 2011, 16% of older homeowners owed more on their house than it was worth. (AARP)
- A majority of older adults have unsustainable housing costs, with 59% of older renters and 33% of homeowners with mortgages spending more than 30% of their income on housing costs. (AARP)
- 44% of African American and 37% of Latino seniors either rent or have no home equity. (Institute on Assets & Social Policy)

NCOA's Role

NCOA offers several programs that provide hope for economically insecure older adults.

Economic Security Initiative

This initiative offers innovative programs in 20 communities to help economically disadvantaged older adults cut through red tape and create a plan to build their own economic stability and security. The service includes one-on-one assistance, counseling, and follow-up as they find job training, assistance with health care and prescription drugs, housing and nutrition programs, and financial planning.

Home Equity

NCOA's Reverse Mortgage is one of eight federally approved national counseling intermediaries. Our 60 counselors in 21 states offer unbiased information to help older homeowners determine if a reverse mortgage is right for them—and what other services and supports are available to help them age in place.

National Center for Benefits Outreach and Enrollment

The center helps organizations enroll seniors with limited means and younger adults with disabilities in a wide range of benefits programs. Since 2001, 3 million people have used NCOA's online screening tool BenefitsCheckUp® to find benefits programs worth over $11.9 billion that help them pay for prescription drugs, health care, rent, utilities, and other needs.

Senior Community Service Employment Program (SCSEP)

SCSEP offers valuable on-the-job training and job placement that helps older workers, particularly those who are low-income or disadvantaged, build job skills and confidence. NCOA currently operates 22 SCSEP a project throughout the U.S. SCSEP is funded by a grant from the U.S. Department of Labor.

Learn more about economic security.

Media Contacts

- Nora Dowd Eisenhower (202) 479-6976 nora.eisenhower@ncoa.org
- Ramsey Alwin (202) 479-6649 ramsey.alwin@ncoa.org
- Maggie Flowers (202) 600-3156 maggie.flowers@ncoa.org

http://www.ncoa.org/press-room/fact-sheets/economic-security-for.html

Health and Safety Focus Group Report

September 17, 2013 11:30-1:00 pm

The focus group was designed to address the concerns that seniors have with meeting their health and safety needs. There were two focus group participants; one had an income below the poverty level, and the other was well educated with a slightly higher income, a little above the poverty line. One identified her health as okay compared to others her age while the other identified her health as poor compared to others her age.

The individuals were asked to discuss their top concern as health care consumers. The two individuals had varying answers. The first person stated:

"I will say dental. It's a big thing here in Nevada. No dental care for seniors."

And the second individual explained:

"Grocery shopping under my circumstances is difficult because of my vision. I used to have what they call a senior companion. It's very difficult doing just about everything because I'm beyond legally blind."

She is legally blind due to Macular Degeneration. She stated that everything is difficult, that she has to be very careful and very aware. She went on to explain she had to stop using her senior companion because the program was now asking individuals to make donations to offset the cost of transportation.[1] She could not afford to make the donation so the senior companion did not return. She has not used the service in nine months. She feels that the people that can donate most get the greatest amounts of help. She also explained that eye care is very costly. She says she has to use a large magnifier at home to read anything, stating:

"And Medicare has nothing for assistance for people with visual problems except cataract surgery."

The second individual discussed some of her health problems. They included arthritis, asthma, chemical sensitivities, allergies, liver cysts, gall bladder problems and Multiple Sclerosis. She does not have enough money to take care of all her ailments so she explained that she takes a lot of B12 and she prays. When asks how this affects her quality of life she explains she cannot travel, she tries to get out and keep going, but because of her allergies she cannot take asthma medicine so this is limiting. She also stated that she does not go to doctors anymore because of cost, and she also is concerned with the attitude she feels doctors have toward her because she is low-income.

[1] This researcher contacted the Senior Companion Director to learn more about donations for transportation. The Director indicated that in some instances they are requesting donations. Generally, this is done when client requests for the services is greater than what is typical.

Cost was a major concern for both participants. The one with Macular Degeneration explains that she has trouble paying for expenses as well, and she has told her retina clinic that she cannot get treatment anymore because she cannot pay for it. Also she discussed having Senior Care Plus, which is a Medicare Advantage Savings plan, but even with having this she cannot always afford her co-pays, explaining:

"If they quote me a price of $175 a month, I don't even get it."

The women were asked about the medications that they take and prescription cost. One individual said she just takes B12 and occasionally Xanax. The other woman says she only regularly takes her blood-pressure medicine, because if she were to take all the medicines she needed:

"It might be $200 a month (response to question how much it would be in order to get all the medications she needed)."

She explained her monthly income before Medicare and taxes are taken out it is about $1200. She went on to explain that while health care costs have gone up, her income has not.

Next home safety was discussed, in particular falls. When asked whether they had fallen in the past year, one of the women explained:

"I just tripped somehow and I went down in slow motion and I fell against the closet door. Nothing happened. Then four weeks ago, I was moving my chair and it's kind of like those captain chairs, and they got the wooden arms. Well I pushed on it and it fell over backwards and I feel and hit my eye right there. I had a nice big black eye."

One participant explained that she feels safe inside, but not outside in her parking lot---

"…the area gets totally black at night without street lights.

When asked if they had taken measures in their home to prevent falls one woman explained how she is afraid to get the suction shower bars in her shower because she was afraid they would come undone. She mentioned there used to be a service that would put in installed shower bars.

Finally the individuals were asked what they would want to tell the Board of Commissioner's.

Three recommendations emerged:

- Explore options for providing low cost dental services to low-income seniors.
- Explore options for increasing the availability of low cost medications for seniors.
- Consider strategies for making eye care service more affordable.
- Educate seniors on fall prevention.

Notes:

Facts about Falls

- **Widespread: Falls are the leading cause of both fatal and nonfatal injuries for those 65 and over**; as baby boomers join the ranks of the age 65+ club, injuries and deaths will escalate. The chances of falling and of being seriously injured in a fall increase with age. In 2009, the rate of fall injuries for adults 85 and older was almost four times that for adults 65 to 74.

- **Very Expensive: $28.2 billion is spent annually on treating older adults for the effects of falls.** Fractures are both the most common and most costly type of nonfatal injuries. If we cannot stem the rate of falls, it is projected that the direct treatment costs will reach $54.9 billion annually in 2020, at which time the cost to Medicare would be $32.4 billion.

- Just over one third of nonfatal injuries are fractures, but they make up 61 percent of costs—or $12 billion.

- In a study of people age 72 and older, the average health care cost of a fall injury totaled $19,440.

- The average cost of a fall related hip fracture injury in 2006 was $37,000.

    - The national 2005 death rate (per 100,000 people) from unintentional falls for people 65 and older was 42.96. Available data for Nevada from 2005 shows the unintentional fall death rate (per 100,000) was 37.90.

    - Nevada state statistics from the Center for Health Data and Research showed 132 deaths in 2004 as a result of unintentional falls. Of the 132 deaths, 70 percent occurred in Clark County; 64 percent of those deaths were people 65 and older.

    - Hospital discharge data collected by the Center for Health Data and Research for 2003 through 2005 showed that 10,035 people were admitted to Nevada hospitals as a result of an unintentional fall. This was 45 percent of all hospital admissions for accidental injuries during that three year period.

Special Population Reports

Age 85+ Focus Group Report

September 25, 2013 at 2:30-3:30

Five individuals attended the focus group, four were 87 years old to 94 years old, and one is a current caregiver to her 85 year old mother There were four females and one male. Three of the individuals are living in an independent living facility in their own apartments. One lives in his own house with his two adult children; he is widowed. The caregiver has her mother at home with her, along with her significant other.

Participants were asked about their living situation. The three in the independent living facility stated they had three good meals a day, were offered non-strenuous activities, and were taken to shopping and doctor's appointments in a 10 person shuttle van. However, it was indicated that about a third of their income went to housing.

The other two individuals owned their homes. The caregiver stated that her mother and significant other live with her, and *"two years ago she (her mother) took a fall. That's the f word for seniors."* The result was she lost her legs. They tried taking her to rehabilitation facilities, but ended up just having her live at home with her. She did have to remodel her home to do so.

The individual whose children live with him was asked if he is supported by them financially and he said, *"None. I support them. We support each other emotionally."* He went on to explain he lost his wife recently after 48 ½ years of marriage.

The caregiver was asked if she needs any help financially and she explained:

"I don't need care but my mom does. She was in places that cost over $6000 (per month) and with skilled nursing it was $10,000 at least per month, and she got no Medicare funding. You get no insurance if you pay for a skilled nursing…..Once you pay for skilled nursing, not assisted but skilled nursing you have no insurance. We were paying $10 for a band-aide."

She went on to explain that she saw people stay in these facilities and spend everything they have and then go Medicaid. She felt some people looked down on those who had gone on Medicaid.

Three of the individuals expressed concerns about staffing in skilled nursing homes. One individual explained:

"They (skilled nursing homes) do not have a very good ratio of caregivers to nurses. You can't even talk to them (the nurses) because they are too busy doing medication or busy doing this or that."

And another said:

"There might be one CNA (Certified Nursing Assistant) to 16 patients."

The individuals were very concerned that there are no state regulations for skilled nursing as far as ratios of patients to nurses/CNAs. One of the people went on to state that:

"The amount of caregivers (staff) in a skilled nursing facility might even be less than at an assisted living facility. There needs to be some regulation to make these people (nursing facilities) accountable for helping these people."

Another concern in nursing facilities is that they have taken the railings off of the beds, because they are considered fire hazards. One of the participants explained that:

"Our state has made everything non-constraint. None of these beds (in care facilities) have railings. So they have these little pads next to the bed if patients slide out. So when mom fell she fell on the floor. This was after she had her amputations and they were trying to change her and didn't have two people like they were supposed to have….They really need a better way to regulate these things and to really think again about railings. They're worried about fire hazards, you know she has no legs; she's not going anywhere…So give her railings. .. She was really helpless because she couldn't get to (call) buttons. She couldn't do anything."

Next, the participants were asked what services were needed in Washoe County to keep people independent. One person stated that:

"I think there should be more transportation available."

Those participants who reside in Independent Living Facilities were asked if they got out as much as the wanted to.

"Oh no, we don't. For all their (the facilities'), activities you have to go according to the schedule the buses are on. If you want to go out to eat, then you get a cab or if you have friends (who drive)."

The conversation then turned to skilled and assisted living. Participants worry if they have to go to one of these facilities or have a mother in one of the facilities that the cost will be draining. One of the individuals explained after a fall she had to go to an assisted living facility for a short-time:

"I said to my son move me to the independent. I can wash myself. I can control my pills, and move me there…..I looked at my bank account and I said I can't afford (the cost of assisted living) I'm going to do my own showering, do my own laundry."

She went on to explain that

"When living in assisted living, you took medications through the ones (nurses) who gives it, you … paid for that service…"the average price around here is$400 a month to get assistance with medications… just for that little service."

The participant explained that:

"If I were to take a shower… two showers a week… I paid for those, $50 usually, well mine were $25….there's a menu of services you pay extra. In assisted living you have a menu to choose from. In skilled nursing you don't. You just get to pay the $10,000."

When the caregiver was asked how services could be improved, she stated that:

"You'll find out when you go to these places, especially all the skilled facilities and rehab places, …there were no pamphlets telling how to negotiate the discussions with staff (relative to costs and services), because there was so much drama every day… you had drama with your loved one trying to figure out if they got their medication, …. where's your clothes, cause you have to paid extra for laundry…..there is no pamphlet in any of the places that we went to ….To navigate the system I would ask questions, but they would ask did you tell the nurse? I didn't know I was supposed to. Well you tell the nurse first, they were in charge of the caregivers. Nurses don't have time to be in charge of the caregivers. It's so convoluted, there is just no way to navigate (the system) and they wonder why people get so upset….There's nothing to help you navigate the system. It's so confusing it would be so helpful to get things plain and simple."

The people living in independent living said they would like to see more services come to them. Now, flu shots and blood pressure clinic are provided at their facilities. However, there is no continuity of care ….For example, when the blood pressure clinic comes, and they are told their blood pressure is high, nothing happens. The people taking their blood pressure cannot actually do anything else.

The caregiver feels the system itself is just too complicated. For example, she has to look too many places for services, and she doesn't know where to look in the first place. Another participant indicated that the information is too diffused, and there is a great need for consolidation of the materials and improved distribution systems so that it can be more easily accessed by people who are burdened by caregiving and not able to leave the house to explore for information.

In conclusion, all the individuals had concerns about care provided in both assisted living and skilled nursing facilities. The people in independent living felt there needs to be better transportation services for them to get out of the house. All discussed that there needs to be better regulations to support the elderly in nursing homes.

In summary, key recommendations emerging from the age 85+ groups are:

- Increase community transportation options.
- Consolidate information on available services, and explore strategies for assuring that is comprehensively and easily available through various vehicles.
- Advocate for improved ratios of staff to patients within skilled nursing facilities.
- Work with assisted living and skilled nursing facilities to assure that easily understood pamphlets are available that explain service options and costs.

Notes:

No Mandatory Ratio

- The law governing nurse staffing---title 42, part 483.30 of the Code of Federal Regulations---mandates no specific ratio of nurses to nursing-home residents. It merely demands that the facility have sufficient nurses to attain the highest practicable well-being of each resident.

Read more:

http://www.ehow.com/facts_6966287_nurse-patient-ratio-nursing-home.html#ixzz2gJ9IZqEV

Hispanic Focus Group Report

September 26, 2013 4:00-5:15 pm

Five Hispanics attended the focus group, all over the age of sixty. There were four women and one man. The meeting was done in Spanish by a translator who wrote notes on what was said during the meeting. As such, no quotes were pulled from the meeting.

There was one married couple present, one recent widow, and two individuals who had spouses. The married couple also had one of their father's living with them; however, they were not his caregiver, and he still works part-time. The widow lives alone and does not have many family members or friends for support. One recipient had an older senior living with her and her husband, and the last participant had a spouse at home. The couple and married participants own their home. The married participants' husbands work.

First, they were asked how aware they are of senior services. None of them were aware of legal aid. The senior living alone was not aware of affordable housing options or grief support groups.

All participants take medications and some, however, cannot afford the costs of the medications. One individual had open heart surgery but had not been taking her medications because she was unaware that there was help to get affordable prescriptions. All participants have trouble paying co-pays. All clients felt they were under-educated on Medicare and assistance to help with co-pays. One member uses SNAP otherwise known as food stamps. One senior is disabled, has an under-age child, has lost two homes, and is receiving Social Security Disability and now has to rent her home. His spouse has private health insurance, but they do not have money to pay for co-pays, and they do not have any prescription assistance.

Next participants were asked whether they used any of the assistance programs. All of the participants are afraid to apply for public assistance, because even if they do qualify, they think there will be some kind of penalty or they are afraid of filling out the application incorrectly. In addition, all participants explained that they are unaware of where to apply for assistance, how to apply, and who is eligible for various types of assistance. All participants stated they are afraid of hidden costs, and only one of the five participants indicated she was content with county services. All participants feel that their biggest obstacles in learning about, obtaining and using senior services are language barriers.

When asked how they get to where they need and want to go, four of the five individuals said they owned a car. The other individual does not have a car and cannot afford public transportation so she depends on other people to give her rides.

When queried about how safe they felt in their own home, three of the five reported they had fallen in the last year. They noted that when looking for new homes, they looked for places that had restrooms with shower bars.

Next participants were asked how they managed their health care costs. Many of the clients go to their country of birth to get dental work done, and, for some, the medical procedures they need. The participants explained that when they use doctors in other countries they often develop new illnesses, and they feel it is due to medical negligence.

When asked about what community services they feel are lacking in Washoe County for seniors they stated:

1) Affordable dental services
2) Affordable health care services
3) Legal Services

When asked about what they would want to tell the Board of Commissioner's they stated that there is a need for affordable medical coverage, that medical insurance has become a privilege, and there should be a public assistance that cover s dental. Also many are unaware of what their legal rights are.

Overall, the participants felt the barriers that existed were:

1) Few providers have interpreters or Spanish-language materials.
2) Lack of awareness about senior services.

Notes:

Department of Health & Human Services

Search

ADMINISTRATION ON AGING

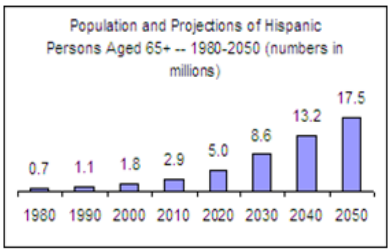
Home > About AoA

A Statistical Profile of Hispanic Older Americans Aged 65+

Introduction

Over 37.9 million Americans are aged 65 and over. Three in five people in this age group are women. Over the next forty years, the number of people aged 65 and older is expected to double, while the number of people aged 85 and older is expected to triple. All Americans are living longer and the same is true for the Hispanic population.

The Older Hispanic Population: Past, Present, and Future



The Hispanic older population was 2.7 million in 2008 and is projected to grow to over 17 million by 2050. In 2008, Hispanic persons made up 6.8 percent of the older population. By 2050, the percentage of the older population that is Hispanic is projected to account for 19.8 percent of the older population. By 2019, the Hispanic population aged 65 and older is projected to be the largest racial/ethnic minority in this age group.

Residence

In 2008, 70% of Hispanic persons aged 65 and over resided in four states: California (27%); Texas (19%); Florida (16%); and New York (9%).

Educational Level

Despite the overall increase in educational attainment among older Americans, there are still substantial educational differences among racial and ethnic groups. In 2008, about 46 percent of the Hispanic population aged 65 and older had finished high school, compared with 77 percent of the total older population. Also in 2008, 9 percent of Hispanic older Americans held a bachelor's degree or higher, compared with 21 percent of all older persons.

Living Arrangements

In 2007, 65 percent of Hispanic older men lived with their spouses, 17 percent lived with other relatives, 3 percent lived with non-relatives, and 15 percent lived alone. For older Hispanic older women, 39 percent lived with their spouses, 33 percent lived with other relatives, 2 percent lived with non-relatives, and 26 percent lived alone. Although older women are more likely to live alone than are older men, the percent of Hispanic elderly men and women living alone is lower than that of the general population. Also, the percent of Hispanic older persons living with other relatives is almost twice that of the total older population.

Income

Households containing families headed by Hispanic persons 65+ reported a median income in 2008 of $33,418 (as compared to $46,720 for non-Hispanic Whites). Among such Hispanic households 19% had an income of less than $15,000 (compared to 5% for non-Hispanic Whites family households) and 48% had incomes of $35,000 or more (compared to 65% for non-Hispanic Whites).

Poverty

The poverty rate in 2008 for Hispanic older persons (65 and older) was 19.3 percent. This was more than twice the percent for non-Hispanic Whites (7.6 percent).

Health

In 2008, only 36 % of Hispanic persons aged 65+ had received pneumococcal vaccination as compared to 64% of non-Hispanic Whites and 43.4% of non-Hispanic Blacks. (2008 National Health Interview Survey)

In 2008, 9.2% of Hispanic persons aged 65+ needed help from other persons for personal care as compared to 5.7% for non-Hispanic Whites and 10.3% of non-Hispanic Blacks. (2008 National Health Interview Survey)

In 2008, 10.7% of Hispanic persons aged 65+ were diagnosed with diabetes as compared to 6.9% for non-Hispanic Whites and 10.9% for non-Hispanic Blacks. (2008 National Health Interview Survey)

Self – Rated Health Status

During 2008, about 66 percent of Hispanic older men and 66 percent of Hispanic older women reported good, very good, or excellent health. Among non-Hispanic whites, this figure was 77 percent for men and 78 percent for women. Positive health evaluations decline with age.* Among Hispanic men ages 65-74, 68 percent reported good or excellent health, compared with 57 percent among those aged 85 or older. Similarly, among Hispanic women this rate declined from 62 percent at age 65-74 to 50 percent at age 85 or older.

Access to Medical Care

In 2007, about 7.5 percent of Hispanic older persons reported that they had no usual source of medical care. In 2000, 6.5 percent reported delays in obtaining health care due to cost, and, in 2001, 20.7 percent reported that were not satisfied with the quality of the health care which they received. The comparable figures for the total population aged 65 or older show that 5.1 percent reported that they had no usual source of medical care, 4.8 percent reported delays in obtaining health care due to cost, and, in 2001, 15.6 percent reported that they were not satisfied with the quality of the health care which they received.

Participation in Older Americans Act (OAA) Programs

In 2008, State and Area Agencies on Aging provided services to a total of 10.6 million persons aged 60 and older. Consistent with the targeting requirements of the OAA, state and area agencies on aging placed considerable emphasis on services to persons with the greatest social and economic need, including members of racial and ethnic minority groups, especially those who are poor. Of the older persons who received OAA home and community-based registered services, 8.1 percent were Hispanic.

The data for this document are taken from a variety of U.S. Government sources with differing sample sizes and designs.
** 2000-2002 data*

The last section, Participation in OAA Programs, reports data collected from State Agencies on Aging about the persons whom they serve.

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: U.S. Administration on Aging, U.S. Department of Health and Human Services, One Massachusetts Ave., N.W., Washington, D.C., 20001; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov

Last Updated: January 2010

LGBT Group Report

October 10, 2013 at 10:00-11:30

There were five individuals who attended the LGBT focus group. They were in their sixties and seventies. There were gay men and a woman, who had a transgendered son. The woman was heterosexual and married; two were widows; one was single; and one was currently in a long-term relationship. They have all lived in Reno for at least ten years.

One gentleman said:

"The gay community around here has always tried to blend in and not stand out."

Another man explained:

"The gay community is a culture shock…..being gay is kind of hard….The community is not political at all."

Another commented:

"There are a lot of seniors here because this has always been perceived as a very safe place to live….where people just live their lives. It's a very much live and let live (attitude in Reno)... If people get to know you first, before they know you are gay, they accept you. They find out and just don't care."

Participants were asked what their key concerns were. One participant noted that there is a gap in social and activity groups in the LGBT community. Apparently, there is a gap in social activities that are aimed at senior Lesbians. There are specific groups like Prime Timers aimed at gay senior men. However, one gap in social activities for all LGBT's is explained as:

"People who are younger than we are don't like older people. There's a feeling when you walk into a bar and you are our age, you can easily be ignored…. One of the biggest problems Reno has is that we don't have a center so there isn't a place to go other than the bars. And that's your choice, which is unfortunate. I don't think that we'd necessarily come to the senior center because we are looking for people who are like us."

Next participants were asked about the availability of support services for senior LGBTs in Reno. One man stated:

"…and when that happened (his partner died) I had all kinds of support in San Francisco, but that's in San Francisco, but here in Reno (there is) no support at all…. (Response to what type of support is lacking) Group support, emotional, professional support."

When asked about senior services in specific, one respondent said:

"In terms of Senior Services for our Community, I think people just don't know about them. There's a senior center, and we kind of know what they do, but they don't reach out to us and we don't reach out to them….. I think … the senior center needs to really reach out to the senior LGBT community."

Participants felt that while there may be services for seniors in general and LGBT seniors specifically, knowing where to go for information is difficult and accessing it can be a problem too:

"He gave me 4 numbers to call. They are either out of service or I never got a call back. And this isn't just the gay community. …We should get a notice of what services are available."

He continued:

"All seniors' need to know what services are available to them. Consider an insert in the newspaper or printout …. that went out to every single household…. These are the senior services that are offered. I know from talking to other seniors in our community…. they know there's a senior center, but they just think it's for providing meals to people. They don't know you only have to be 60 to come down and socialize. They think you have to be destitute to get any of the services."

Participants mentioned that there have been significant changes in the past few years in how they access information:

"I miss the paper. We had gay papers. …. I miss that because that's where I got all my information. That's my main problem, how do you get the information. You have to go on the machine (computer)…. I think the issue for seniors is that you have to be connected to the internet now. Whether you want to be or not…. That's where to get your information because that's where everything is headed."

The on-going financial crisis has had a significant impact on their economic security. They report that they are struggling financially.

"Even though my assets are some houses that are under water, they are still considered assets."

He was stating that he cannot qualify for any income-based service because of this house that he owns. He also commented:

"I pay most everything out just to have a roof over my head so that doesn't leave a lot to live on."

Plus:

"When my lover died all his money went to medical (expenses) because he didn't have any insurance. So he had to pay out of his pocket…. It ends up being a big drain to people…. Here in Nevada, you don't have the medical benefits in other states."

One man explained the burden his mortgage by saying:

"I'm not well off financially, because I'm paying the mortgage by myself."

The issue of bullying was raised as a serious problem. It was brought up by the mother of the transgender son. She worries when her child goes out that people will be able to tell that she is transgender and that someone is going to end up hurting her.

Another respondent explained that:

"It still happens… yes…. because there are those people that think it's funny and cute. Bullying is a big thing."

Some of the seniors discussed the isolation they feel being in Reno as an LGBT senior. One man in particular explained it was so hard for him because:

"Well, this is the first time in my life I've lived alone. It's scary because I've never lived alone."

Another gentleman said:

"I like having someone around to do things with. I like to go out and do things, but then I come home by myself. I like being (taken care of) and taking care of someone."

Of all issues raised during the focus group, the most critical issue was transportation.

One man explained:

"Public transportation is good, but it doesn't go anywhere you need to go. If you do get a bus that goes there, it runs every hour. This is something that should be addressed."

While another said:

"Transportation is not a problem for just our community, but seniors in general. It's hard to get around. For me to take the bus, I have to walk almost a mile and a half to get to where the bus comes. "

While another gentleman explained that using public transportation limits his activities because:

"Yes, it does, because I would be able to do a lot more….based on the location, you'd have to leave at 9 am in the morning in order to get there for the 1 pm lunch…I think that access should

be looked at. If you need to go from point A to point B, it needs to be more readily available and at a more affordable costs because if you qualify for using ACCESS you should qualify for less of a payment because you don't have the money to begin with."

Using public transportation during the winter seems to have some added challenges for seniors of Washoe County. One participant stated:

"If you live on a snow route and need to go somewhere and it snows, you won't be able to get home."

Another said:

"I'm afraid to go down sidewalks when it snows. I have a deathly fear when there's ice."

One man mentioned that to come to the senior center for a $2 meal for someone that takes ACCESS he believes:

"But still $8 a day that's expensive for a senior."

Explaining that he thinks it is $3 each way for a $2 meal, and how this is very expensive for a strapped senior to pay. He also went on to explain that he thought this is a hard problem to solve because:

"Have to rely on people to raise their taxes. Well, nobody is going to want to pay taxes for a service they don't use…..most people don't use the bus."

Timing of the buses also appears to be a problem. One gentleman explained:

"It takes me an hour or an hour and a half to get to the VA Hospital…..…..you have to transfer and, if your bus is late (and) the other bus leaves, you have to wait for another hour."

Another individual reports:

"I have a car but sometimes I don't have the money to buy the gas. It's just a little bit expensive for the gas….That's another thing for seniors on a fix income. They can't afford gas."

The participant went on to explain that sometimes the price of gasoline is such a burden that it affects him being able to leave the house and do activities:

"Well, yes. Now I can't go out to some of the activities anymore. When you are used to having two incomes all these years, it's now one less income."

In conclusion, the LGBT focus group made the following recommendations:

- Expand the availability of senior transgender and lesbian social networks and groups.

- Expand affordable transportation options in Washoe County, with particular emphasis on underserved areas.
- Expand options for distributing community information about senior services, especially through vehicles that do not rely solely on the internet.
- Expand affordable services to low-income seniors who are slightly above the poverty level.

Notes:

http://www.advocate.com/society/people/2013/09/02/prime-timers-spotlight-lgbt-seniors

Prime Timers: Spotlight on LGBT Seniors

BY Sunnivie Brydum

September 02 2013 6:00 AM ET

While the nation embarks on much-needed conversations about marriage equality, creating safe and supportive schools for LGBT youth, and securing nondiscrimination protections for all LGBT Americans, there's an undeniable urge to look forward.

But as we look to the future and are hopeful for the change that's already coming, we here at *The Advocate* wanted to take some time to look back and reflect on those who came before us, and those whose bravery, persistence, and dogged determination paved the way for us young radicals to proudly stand up and proclaim, "We're here, we're queer, we won't settle for anything less than full equality!"

Led by an intrepid young staffer, *The Advocate* team embarked on its first-ever week-long series focusing on LGBT people over the age of 65. Our Prime Timers collection focused on individuals, groups, and projects that explore what it's like to hold an older identity in a subculture that's perpetually fascinated by youth. Keep reading to find our full Prime Timers coverage, including profiles, film reviews, and op-eds from our esteemed elders.

Prime Timers: A New Age for Activism
From authors and actors to artists and advocates, we've gathered 25 LGBT people over 65 who are living proof that life, like wine, gets better with age. Upon reaching official retirement age, these trailblazers stepped up their activism and influence to become icons in the ongoing fight for LGBT equality. From Alice Walker to George Takei, from Edie Windsor to John Waters, these are the LGBT seniors you won't soon forget. Meet all 25 here.

Op-Ed: Seniority at *The Advocate*
The Advocate's esteemed senior Web producer, who's been with the publication for more than 20 years, reflected on his unique perspective on history as he's viewed it from his desk — which used to be a drafting table where he studiously composed layouts for issues of *The Advocate* by

hand. Christopher Harrity brings his characteristic wit and world-wise perspective to this rare op-ed from one of *The Advocate*'s longest-serving and most respected team members. Read it here.

9 Tales of Young Love and Old Memories

Hollywood's Triangle Square, founded in 2006, is one of the nation's only affordable housing options dedicated specifically to serving LGBT elders. Operated by Gay and Lesbian Elder Housing, the Los Angeles residence is full of characters with lifetimes of stories to share. Two *Advocate* staffers spent the day at Triangle Square, where residents served our editors tea, cookies, and cupcakes as they shared stories of first loves, coming out, and finding themselves as LGBT people and as seniors. Read nine touching stories, accompanied by exclusive photos, here.

Op-Ed: 72, Transgender, and Finally Myself

Rosie Del Mar joined the Army at 18 less out of a desire to serve her country, than from a desire to hide her burgeoning sexuality and gender identity. By the 1960s, Del Mar had found a word for who she was — transgender — and was undergoing therapy for gender affirming surgery that she says never materialized. While Del Mar's sincere story chronicles the times she was threatened by lovers, police, and even members of her own community, her tone is ultimately triumphant as she revels in living her golden years authentically. In addition to being an outspoken transgender activist, Del Mar is also a resident of Hollywood's Triangle Square. Discover how Del Mar found herself here.

***Before You Know It:* Film Reviews Gay Lust for Life After 65**

Anyone who thinks that your passions drift off into obscurity after 65 clearly hasn't met the subjects of *Before You Know It*, the compelling documentary on life, love, and aging in the gay community from 30-something filmmaker PJ Raval. Through intimate portraits and stunning cinematography, *Before You Know It* introduces its audiences to three gay men whose lust for life is growing along with their age. Meet the film's subjects and explore the inevitability of aging — and why we shouldn't fear it — here.

HHS Offers Benefits and Joint Placement to Married LGBT Seniors on Medicare

Someone at the Department of Health and Human Services got our memo about the Prime Timers series last week, since the federal department announced new benefits directly impacting married LGBT seniors on Medicare on Thursday. In the wake of the June 26 Supreme Court ruling that struck down a key section of the so-called Defense of Marriage Act, HHS will now offer equal benefits and joint nursing home placement to any legally married same-sex couples who are on Medicare, regardless of the state in which they live and whether it recognizes same-sex unions. Find all the details about the department's historic decision here.

Excerpt: Awakening The Woman Inside

Before she was a classically trained violinist, an accomplished artist, or an out lesbian, José Beth Smolensky was the wife to a cheating, abusive husband. She obeyed him and stood by him until she could take no more. Upon leaving him and trying to forge a new life with her four children, Smolensky was introduced to Miami's lesbian scene, a life-changing moment that helped her move on and eventually find Pat, her partner of 33 years. Read an excerpt from Smolensky's new book, *Hide and Seek: Out of the Darkness and Into My Life,* here.

Op-Ed: In Defense of Aging

In a gay male culture that's perpetually focused on youth, how does one come to terms with the reality that someday, we all get older? That's what contributor Jon Bernstein, 47, ponders in this inquisitive op-ed. As a survivor of the early stages of the AIDS epidemic, Bernstein reflects on the generation of would-be elders lost to the disease, and the harsh reminder of mortality the epidemic continues to foist upon the community today. Calling out gay culture as perhaps suffering from Dorian Gray syndrome, characterized by narcissism and an obsessive physical pride, Bernstein argues that perhaps gay men would be better served by striving to embody one of Oscar Wilde's most poignant messages from that seminal novel: "Live! Live the wonderful life that is in you! Let nothing be lost upon you. Be always searching for new sensations. Be afraid of nothing." Read the whole article here.

Rural Focus Group Report

October 4. 2013 at 1:30-3:00

Two individuals attended the focus group, both were in their seventies. They are husband and wife. They reside in Cold Springs, on a half-of-an-acre lot. They have lived there over 25 years. She had retired on disability, but when she shifted to Social Security, they no longer could afford to pay their bills so they have done a reverse mortgage. They like the quietness of being out in a rural area explaining:

"Peace and quiet and having the smell of pine trees. When things happen in the sky you can actually see it at night."

When asked about services, one participant replied:

"A lot of people want the bus to come out here. I was told by RTC that people would have to literally write letters. The more letters they got about people who wanted service to come out …..it had to be a certain percentage….the more likely something would happen."

When asked what the biggest problem they experience in living in a rural area, one participant explained:

"The main thing we have trouble with is .... Is there anybody that you can call such as hired electricians, plumbers, or people with their own landscaping business… We can't afford this. For example, I blew a light fixture in the dining room about a year and a half ago. Normally, my son would fix it, but he had back surgery and can't do anything. We can't afford to hire an electrician. It would cost more to hire an electrician to put in this light fixture than to buy the light fixture itself….. I was hoping to get something out here for seniors ….. maybe a senior discount or a handyman's service. I'm sure with all the seniors living out here, we could keep someone quite busy. But you get kind of scared also like what if you don't hire the right person and they come back (to commit a crime.)"

The woman went on to describe how they used to receive help from their grown son, but he has recently been injured:

"Since my son got hurt, we really have noticed that we just can't get things fixed….Painting your house it just takes a lot of time. If you have someone come in you are talking about $1600. If there was someone that we can call that we can trust that didn't charge an arm and a leg or charge you $85 just to come out and look at something. You're just at their mercy. Oh we don't come out there or we charge extra."

They feel they have less physical support living in a rural area…. less help in general. The wife explained her fear of her husband doing some of this fixes himself saying:

"When he's doing stuff like that, he can't be out there by himself. So I'm standing out there."

The participant felt there should be volunteer programs that offer these services to seniors. In addition, he went on to explain that he has diabetes but the hard work of yard maintenance causes his blood sugar to drop, stating:

"I have diabetes and sometimes I wake up and I'm 200 (blood sugar level), which is pretty low considering. But when I come back in the house (after mowing the yard), I might be 52. Just working outside my blood sugar will go way down. I go inside and sit for a couple of hours and then go back out there. It's just kind of hard."

The wife explained that her husband's health issues are a concern because they live so far out of main town:

"If his knee gives out on him; it scares me when he is up there (the roof) you know. If his knee gives out on him then what happens. He's going to roll off the roof."

Participants also discussed the economic hardship of living in a rural area. They know it is cheaper to live outside of town in terms of housing costs, but because gas is so expensive they do not drive much. One person explained it is difficult to be far away from needed services, and, given the distance they have to drive to go to appointments, this can be a financial hardship:

"Everything (stores, gas stations, etc.) …. everything is so expensive. So if you want to live out here (Cold Springs), you have to pay the price."

She went on to explain that they initially moved to Cold Springs because home prices were significantly cheaper. However, many people do not like to live there because nothing is around, but they have been living in a rural area for over twenty years. She explained that if you want to sell your home, there is a problem:

"People don't want to live out there because it's so far out. That's why it takes forever to sell."

They had considered selling and moving into town but explained:

"We thought about moving back into town to be near our grandson. When we started looking at houses I said I don't think I could live so close to people. The houses were that far (indicates small area with her hands) apart."

They went into more detail about the impact the cost of gasoline has on their daily lives, stating:

"We don't drive all that much. The gas is ridiculous. It's nobody's fault. It's just the way it is. There's two little mom and pop shops that sell gas (out here) and one is ridiculous. We actually wait till we come into town for something and then we go to Sam's Club because it's the cheapest (gas) we can find."

They explained that Lemmon Valley, which is about 10 miles away from their home, is the closest location for shopping for groceries and pharmacy. Their doctors and dentists are far away in the south part of Reno and Sparks.

Also, there are no entertainment options near them. They explained that the distances to services limit the number of trips that need to be made saying:

"We didn't want to change doctors so we just have to pay the price. When we do go into town we just do more than one thing. There's really nothing out there but a 7-Eleven."

As far as financial help or assistance, she explained that they have not used any services because they make too much money to qualify. She explained in more detail:

"I've been on disability since '97. I was getting disability pay, but when I turned 65 that stopped. The way it was explained to me is that money I would be getting from Social Security to make up for that. Well that didn't happen. They put me on Social Security but they didn't increase the money. That was about $450 a month that we lost."

She also worries about transportation:

"I worry about what's going to happen when I can't drive anymore….How are we going to get back and forward to town… it will be a big concern. I would hesitate to take the bus (ACCESS). Only because when my mom used it when she lived in Sparks, and she would spend most of her days just sitting and waiting for them to come back and pick her up….We know it takes people to appointments and the grocery store and etc. If it's still like when she used to use it, then you have to make a day of it. I just don't like the idea of counting on someone else to get us around."

Although they still say they would want to live in a rural area saying:

"Now if you ask us if we'd trade living in town for all this, we wouldn't because we love it out here,"

She further explained that people that live in the rural areas help each other:

"There's a group of seniors out here. We try to help each other. When I had my knee replacement, I had some of the people drive me to the rehab, and they took us to the grocery store. That's just our little senior group out here, and we just call it senior hangout. At least you have a little emotional support."

When asked about the future and living in a living facility it was stated that they did not want to because then it is like you have been forgotten. Further, when asked about if one were to pass away would the other stay out in the rural area it was said:

"I would to because all I have to pay is taxes."

Going on to say that rural neighbors are real protective of each other, and for instance they would check on you if they heard gunshots in the middle of the night or something of that sort, explaining:

"We sort of jump on things, we sort of help each other out. We figured that the word got around that that's not a good street to rob. We haven't had any problems since then."

They went back to discuss that with the distance it does make it hard to participate in some activities and services, stating:

"We are not going to make a special trip just to go to lunch. If there are other things to do then we'll do it."

They did discuss one social group that they meet with:

"The senior group that meets out there on Saturday, it's not only some people come from valleys, Red Rock... everybody out in the valleys. Some of the gals are widowed so they only have themselves to depend on driving anymore. A lot of people only one person can drive anymore."

The pair was asked about fall prevention they have taken in their home next. They explained they have added things to the house to help protect against falls such as replacing the tub with a shower.

Finally they discussed that they do wish there was more social or entertainment type of venues accessible. That there are a lot of seniors in Cold Springs, and the only people they can depend on is their senior neighbors.

Key issues that were identified in this focus group are:

- Expand transportation options.
- Increase the availability of affordable home maintenance services.

Notes:

Nevada-Senior-Guide Chore Services and Home Maintenance Directory – Northern Nevada Rural

Posted on August 10, 2011 by Leigh St John

Churchill County Senior Center Volunteer Program
310 E. Court St., Fallon, NV 89406
(775) 423-7096, Ext. 22 Churchill County
Meals on Wheels, Lunch M- F, Socials, Blood Pressure Support Group
Community Home-Based Initiative Program

(CHIP) – Carson City
State of Nevada – Aging & Disability Services Agency
Northern Nevada
(775) 687-4210 Carson City County
(775) 738-1966 Elko County
(775) 688-2964 Washoe County
www.nvaging.net
Homemaker services, Rx, Elder Abuse
http://nvseniorguide.com/2011/08/nevada-senior-guide-chore-services-and-home-maintenance-directory-northern-nevada-rural/

Provider Group Reports

Health Care Provider Focus Group Report

September 20. 2013 at 10:30-12:00

Three providers attended the focus group, one was from a non-medical home care provider agency; one was from a medical clinic; and one was a provider of an adult day-care service agency. One individual was an RN, and the other two were agency directors. Two were from profit agencies, and one participant was from a non-profit agency.

First they were asked about challenges they face while providing services to seniors. One participant stated:

"We have a challenge recruiting and retaining physicians, nurse practitioners, and physician's assistants, and that is a problem throughout the state of Nevada. It's even worse in rural areas, but difficult in all of our communities so we work with the state of Nevada on the provider recruitment."

She went on to explain that there is a stigma with using her clinic since it is a federally funded health center. She indicated that some people think it is just for the uninsured and poor. She also said there is a communication problem about what services are available and who they serve, even though the center has employed direct mail, free media, medical provider presentations, facility tours, and public presentations to educate the community, confusion still exists. The cost of services is based on a sliding-fee scale; however, there usually is $40 co-pay. Sometimes this can be waived depending on the circumstances of the client, but many clients feel stigmatized since they view it as not taking care of themselves.

The non-medical provider explained that one of their biggest challenges is staffing. They cannot recruit enough staff to meet the client demand. Cost also can be a burden for some lower income clients, because the cost varies depending on insurance, diagnosing, where referral came from. Furthermore, the pay for some positions, such as home care workers, is low and lacking benefits. The medical clinic representative agreed that there is a lack of providers and stated that especially now with the Affordable Care Act, there will not be enough providers and primary physicians to see all Medicaid patients.

When asked about possible solutions to some of staffing issues, one provider explained that in order to reduce turnover in his company:

"*We ask a potential employee to volunteer for 10 hours before they actually sign on."*

The medical clinic participant explained:

"Over the last couple of years, we've focused on building our teamwork. Our medical providers all have workgroup meetings twice a day to coordinate care ….. We're completely converted to electronic health record. We're trying to stay ahead of the curve. So, providers feel they are working with an organization that is really moving with the times providing high quality care. We've also increased our provider involvement and quality improvement work. Asking for them to make a personal commitment to the growth and strength of the organization is helping people feel … important which is particularly critical in an organization like ours."

The participants were next asked about the health status of clients. The medical clinic participant explained many of her clients are low-income, with fair to poor health and multiple health issues, and social service needs. She described her case load as 120,000 clients per year including WIC (Women, Infants, and Children). The non-medical home health provider explained that his clients' health is poor to fair and that they need help with their ADL's (Activities of Daily Living). He occasionally deals with healthy clients that just need companions. On the other extreme, he deals with clients who have end of life issues. He described his caseloads as 2100-2200 hours a week for the whole company. Another problem he has is that many people with private pay can't afford the cost of services. He noted that many clients and potential clients do not know where to go to get help, especially if they are already isolated. He went on to say that they are not aware of government services. When he goes for a home visit, he tries to have back up resources and plans for these individuals. He explained that there seems to be a lack of resources. There are individuals who have been abandoned by their families, and many of their friends have died. Many senior are not internet savvy and do not know where to go.

The participants were asked about their growing needs. The medical clinic participant explained,

"We are seeing growth in all age groups in our practice. We are busting at the seams for space, and our providers are much stretched."

She went on to explain that they are in need of physicians.

Another provider said:

"We have added conference room for training; we felt that was extremely important to support the caregivers (through expanded training opportunities)."

When asked about where there is still room for improvement, participants commented that coordination of care is important. The medical clinic participant explained:

"We are also integrating more of those services into primary care… so primary care is not just sickness care. …It's not perfect, but we've made tremendous strides in coordinating our services with other agencies to ensure that it is as seamless as possible to the patient."

Laws and regulations were discussed as barriers to helping some clients and to running a more efficient business. For the medical clinic participant, one of the biggest problems is that they

cannot bill Medicaid for two different services in one day. For example, when a child goes there for a physical and the medical staff discovers that he has an abscessed tooth, they cannot just go over to the dentist that day because the clinic cannot bill for the physical and the dental visit on the same day. There were some other feelings about laws and regulations including some problems with how the TB testing for employees is handled:

"Make the law more specific or train their Surveyors to be unified (in applying the regulation). We'll have safer application of the laws,"

And:

"We are regulated by the state in the sense that we have to send our caregivers off for state and federal background checks…This is an added expense and is a burden to the company. Furthermore, we have to be very careful to ensure that Personal Care Assistants do not assume medical duties.

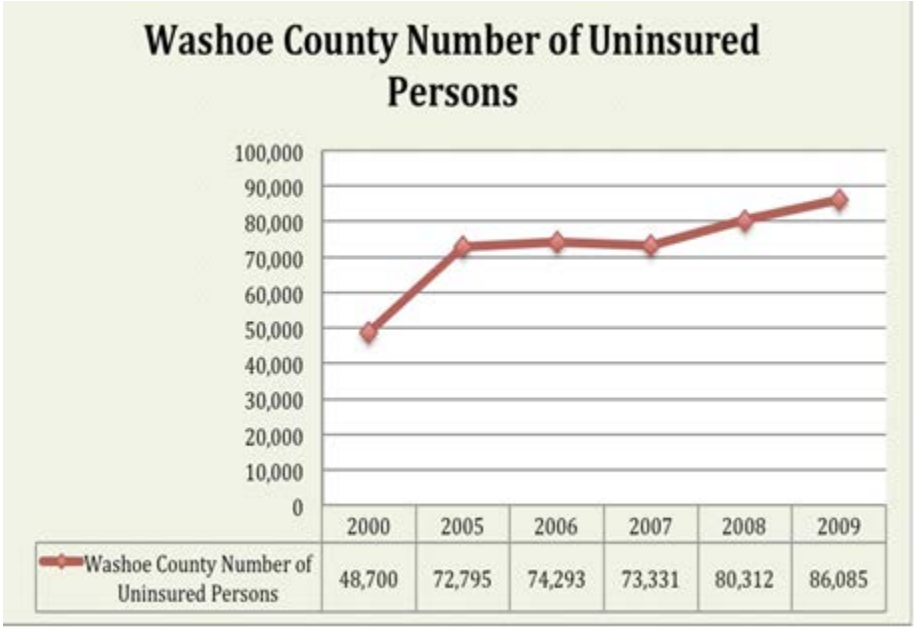
Another individual stated:

"There are some … laws that define the do's and don'ts that don't make a lot of sense…, tremendous regulatory requirements as well as state oversight."

The participants were asked to think about future needs and to define priorities for action:

- Refine available Information and Referral Centers to enhance their ability to help seniors locate services that best meet their need.
- Fully staff I and R Centers so that seniors seeking services always deal with a "live" staff member rather than a recording.
- Create a network of services so that provider can easily share key client information.
- Create a website on state laws and regulations to help providers interpret and implement requirements.
- Create incentives for professionals and para-professional to work in the health care field.

Notes: This graph is for all populations of Washoe County not just Senior Citizens that need to use facilities such as the medical clinic.



Advocates Focus Group Report

October 14, 2013 2:30-4:00 PM

There were five providers who attended the focus group, two women and three men. They represented a disability law center, civil rights group, AARP, advocacy group, and the National Alliance of Retired Americans.

First, they were asked about the needs of seniors in the county. They had a wide range of answers. One participant said:

"I think that the needs for seniors are similar throughout the state in the sense of lack of information on what the resources are, where they are located, and how to access them."

Another provider explored the idea that some people have the resources (money, information, knowledge) that they need to live comfortably and others seem not to. Then he explained himself further with:

"There is definitely a haves and have not's. There are people for whatever reason has the ability to find the information. Unfortunately, sometimes but not always, those with money can find things and those with no money can find things, but sometimes that middle group really has problems."

The third individual felt that the Washoe seniors need easier access to the services that are available. He felt:

"I think access to services is really important. You absolutely must have an advocate because you don't know what is going on….I think (the availability of) advocates is one of the deficiencies, it's major. And we're not an advocacy agency, but my wife spends about 30-40 hours a week advocating for seniors statewide. And the reason is, because they can't find advocates at the local level. They don't know how to do it or they find advocates who are specialized for certain things, for certain age groups, or whatever. There are very few general advocates out there."

The fourth stated:

"I think medical facilities keep slashing the number of personnel that they have, and expect (those who are left) to do more. With fewer of them to do more, this leaves more room for mistakes. I've experienced it myself with mix ups on medication, my charting was wrong, so therefore I myself want a senior advocate. And I can see where seniors would really feel a lot of anxiety and confusion. This is an area where seniors really need (help). Another subject related to this, I've had friends lately who have put their relatives into rest homes or nursing homes …. This is really a confusing situation to go through…This is a situation that the average person has a difficult time navigating."

Finally, the fifth provided expressed the following:

"One of the problems I'm seeing is that we expect seniors to access (services)… instead we should access seniors (where they live). So, the models are all broken, because no one wants to go to the senior and tell the senior what is available. We expect the seniors to get to somewhere. We expect the seniors to access the traditional law firm model and that's ridiculous."

The inability for some seniors, especially at risk seniors, to access services was a fairly consistent topic. The group explored what some of the barriers were and one person said:

"We assume everyone has cell phones, everyone has access to a computer, and I'm finding, a lot of times, they don't even have access to a landline. So, we expect them to access all this stuff and they don't. They don't have the ability to do that. If you don't bring it to them, then it's not going to get to them. There's a lack of community outreach to them. Sometimes people don't know what they want to know, and that's an issue. There are a lot of people on the other side of that barrier that might have benefitted, but they didn't know what was going on. You can't force it on them, but (WCSS needs to investigate) how you bring community outreach to the people that need help."

One other participant pointed out that we really are talking about specific group of seniors when we talk about accessing services, explaining:

".. If seniors have access, sufficient income, they don't need what we are talking about."

One member discussed the cultural differences in America in regards to how seniors are taken care of on a whole explaining:

"Families aren't inclined to take care of the elderly like many European cultures. A lot of seniors are on their own. So, I think it (the need) has become more community oriented. The community ends up picking up the pieces….But here in Nevada, we have something more unique, because a lot of seniors come here to retire, particularly Las Vegas. So they are separated from their families when living in Nevada."

The providers also discussed ways to get services or information out the residents of Washoe County who do not have sufficient access to transportation. One person said:

"A lot of these people who are socially isolated who might listen to the radio, might watch T.V. if they saw it they might be like oh 211 (referring to the human services hotline)."

Another person asked:

"Why isn't Nevada Power assisting in delivering information to the seniors?"

One provider explained his frustration with no quality, central place to go for resources, stating:

"The structure, the function so much more, varies from state to state and even in states. Some states, I don't know why or how have very functional ADRC systems. Nevada has been a true trial. Nevada hasn't been able to do it anywhere whether it's in Clark County, in the rural area, or in Washoe County. They just keep spending money and a lot of money they spent should be giving seniors some results and they are not. That's been going on for 10 years maybe not quite that long….The models that they have been using just don't seem to be that effective where states that have Area Agencies on Aging have an advantage for whatever reason if they can leverage community resources, I don't know ….. But I know that the ADRC have been a significant challenge in the state of Nevada…. They spent over $10 million on that program, here. Now that's going back to the year 2002. It just a whole lot of money being poured down a rat hole….Maybe they can look at different models or something. They just keep trying to fix up what they have, let's build this, let's remodel, let's put another coat of paint on it, let's do something different, and it looks very different up here then down south….They just keep trying to cobble it together instead of looking if there a different way or a better way. Do they start over I don't know. We all hear about the dysfunction but none of us are being part of the process to fix it. It's just not productive. There is no desire on the part of the people managing the state to make it productive. In fairness to them, it is in some case they are not competent enough to do something. It requires a certain technical expertise if you are going to set it up and organize it."(See State I&R Plan)

Next the discussion moved to transportation. The first individual compared Washoe County to Clark County (Las Vegas), by stating:

"Up here it's even harder because you have the distances that you don't have down south. The real issue is funding. I don't think there's a lack of desire by as much as there are fewer dollars and cents."

Another provider explained that we can't just focus on the basic transportation needs of seniors, such as accessing food and getting to doctor's appointments, but also for social activities, they said:

"Seniors are just like everyone else around this table. They like to get out and enjoy the benefits of the community. It's the nature of what they want and matching transportation so they can live a normal life."

One person disclosed that impact of not being able to drive can have on a person. Telling the story of one senior in particular:

"She can't drive. She's isolated and her kids are taking advantage of her."

Next the group discussed respite care and described the importance of respite services to the caregivers. One provider explained:

"There are some programs where family members can be paid attendants. There is respite money with some respite programs with various resources. Whether Medicaid does that or they want to apply to some state program to add that as one of their approved services. There are other states with tax credits for caregiving. Some states just recently passed that law….. Not going to happen here."

Where another said in regards to businesses supporting their employees when they need time off for caregiving functions:

"Businesses are afraid, you would think that they would rather have healthy employees that were utilizing their paid time off appropriately as opposed to being afraid their employees are going to rip them off and take days off when they don't need to. You don't really want to explain family caregiving is not taking time off to drop your kid off at school. It's taking your mom to the doctor when she has cancer..."

Housing was the next topic of discussion. The group talked about housing issues that they see in Washoe County for seniors who are struggling financially. One participant noted:

"I have an individual who is prepared to come up here and take a very old casino building and renovate it and turn it into senior housing, but he has got no support from Washoe County. He's not going to go through 2 years of zoning and everything else. He has the capital to renovate the facility….So unless the county and municipalities are willing to provide the leverage that they need to renovate, they are not going to renovate."

Another person said:

"*I'm not going to build anything. You have the facility sitting in your county that is ripe for renovation. Why do we need to build again?"*

Another participant stated:

"There are 6 senior centers, not community centers, in Washoe County that are totally underutilized. Inventory everything the county has… that can assist in providing the nourishment out to seniors."

In conclusion the providers feel:

- Emphasis should be placed on upgrading and coordinating information resources beginning with problem-solving the ARDC website.
- Expansion of transportation services should be made a top priority.
- Investigate options for converting currently unused building into senior housing.

Note: This is the link to Washoe County Senior Services and their ADRC:
http://www.washoecounty.us/seniorsrv

Guided Conversations

Information and Referral Guided Interview

Two issues, transportation and information and referral, were issues that emerged as high priorities in both the focus groups and the stakeholder group discussions. To get a better understanding of the issues confronted by providers, a guided interview was convened with three providers from State ADRC, Washoe County ADRC, and the SHIP Program. Each of the participants worked in the field for some time. One respondent has worked for 23 years while the newest one had worked 1.5 years.

When asked to describe the history of her program, the State ADRC representative said:

The Aging and Disability Resource Center started out as the Nevada Care Connection, a caregivers' website. There were three sites that operated in the state. It only had funding for three pilot sites. They were to provide information, provide options counseling, review options available to people, community supports, and benefits counseling. Federal support was used to operate these sites. There are now seven sites in the state. Each site counselor must be certified in Medicare. In total, there are 19 programs that the site counselors must be proficient to refer clients to. To the extent possible, we don't want to hand them off to different providers. The goal of the program is to expand to other sites in the state.

The SHIP counselor indicated that the primary goal of their program is to inform persons about their Medicare options and to answer questions that they may have about the various programs. They also try to locate the Medicare Plan that best meet the clients' needs. Their recommendations are neutral and not biased toward a particular plan. He indicated:

Medicare is very scary to people. It's almost impossible to get the word out that we (SHIP) is available.

The Washoe County ADRC is the entry point for local residents. The counselor for the program said:

I am pretty much the entry point for seniors, caregivers, and the disabled. We provide information that can vary from "Where's the welfare office?" to "I need a new house." So they'll come to me. They will get a form at central reception. Then I will see them, and screen for what they are looking for. We will discuss their needs and that is when I do the options counseling. I go through the eligibility, but I don't determine whether the person qualifies for the particular benefit. I don't share my opinion. I work with them until they are stabilized.

They were next asked what they believe have been their greatest successes. The State ADRC director commented:

Initially, the goal of the ADRC was to get an online portal with a resource directory. We started to expand. We now give providers more comprehensive information on the target population, the elders, the people with disabilities, and people planning future supports to keep them in the community. It started out as a resource directory and it morphed into many things. We have to have community support such as people updating the Golden Pages. Another success has been getting buy-in from the community.

The SHIP coordinator indicated that their greatest success is:

Getting seniors Medicare. If you get someone coming in and you are able to get them good health coverage, good drug coverage at an affordable rate…and they walk out with peace of mind. Before they became eligible for Medicare, they haven't gone to the doctors for years.

He also noted that he helped two clients who were being abused, and he felt that was a great success.

The local ADRC coordinator believes that having available on-going training is a success of the program.

Training because I am relatively new in the position. So many needs, so many resources, so many programs, and so many different questions that I get. However, I do get continuous training because everything is always changing, its fluid.

When asked about the challenges they experience in delivering services, the state coordinator said:

Lack of staff that is needed to do the work, time is always our enemy…Lack of funds is always a problem.

The SHIP coordinator said that his chief problem was:

Finding the right organization to refer people to…. you are dealing with people specific problems…when you need something it is not always there. We don't want them giving up. We want to do less referring. Another challenge is working with the seniors themselves. Seniors tend not to be comfortable with technology and they are cautious by nature. It is a problem to get seniors to buy into us….the bottom line is that it is a challenge to get them to trust. Some medical conditions are very touchy subjects. We also have a problem reaching rural residents.

When asked about outreach efforts, all three participants indicated that it is a problem due to limited funding and staff. The local coordinate would like to do more outreach through the Hispanic channel and through their local newspapers. The SHIP volunteer indicated that Medicare sends out some information about the availability of SHIP services, but he believes that more should be done.

Transportation

Two representatives from RTC participated in our guided conversation on transportation. They were first asked questions about their sources of funding.

"We get a variety of state, federal and local funds for transportation. Our transit is primarily funded by our local sales tax and that can be used for operating the buses or providing service. We also have a fuel tax that can be used for road way improvements, and preventive maintenance."

They were next asked to comment specifically on what sources of funding are used to operate the buses:

"Last year we received a grant…for $5 million dollars. We are able to get hybrid fuel efficient buses that are saving us money and replacing older buses."

When asked how RTC specifically supports senior transportation, they said:

"In a variety of ways. 2 million senior or disabled riders on the fixed route out of 8 million and on ACCESS 200,000 people and most are either seniors or disabled. There are also resources applied to Roadway Improvement, Sidewalk Accessibility, and Intersection Improvements. All of these efforts contribute to the safety of seniors."

When asked what their greatest challenges were in offering services, they said:

"Funding is a particularly big challenge in the transit operating side. Because of the recession there has been a lack of revenue from sales taxes. We do receive $20 million dollars from sales taxes and an additional $6 million from fares."

They were next asked about what the future of transportation services for seniors would look like in the future:

"It's going to be a combination of trying to get all the aspects of transportation to work together. Starting with the sidewalks, so people can have that accessible pathway to the bus stop…we hope to continue operating fixed bus services to seniors….the fastest growing demand is para transit. The demand for para transit will double in the next 15 years."

She went on to say:

"When you start talking about aging, you don't have just one disability, you have multiple disabilities. To meet the needs of seniors, we are adding more bike lanes, better lighting, getting buses that are easier to get on and off of, wider intersections, and circulator routes for outlying areas."

When asked if they served the area tribes, they replied:

"We only provide services to the Reno-Spark Indian Colony. A certain percentage of funding goes there, but they do not provide transportation services themselves."

When asked specifically about benches, an issue that rose during one of the focus groups, they said:

"We have a bus stop amenities program. We are trying to place benches in places where are a certain number of boarders or when we know there is a need. We are sometimes restrained by the physical space available or the lack of boarders, but RTC is in the process of trying to get benches for most stops."

There has been discussion about cutting fixed routes and imposing higher eligibility standards of Access. They were asked to comment on these options.

"Several options are being developed of the RTC Master Plan. We are looking at an impending funding short fall, we are trying to come up with a full range of options to address that, and these are just two of the options being considered. They are being presented to the board for their recommendations and how to incorporate them into their operational budget."

When asked about how much they would need to rise to operate a volunteer assisted neighborhood circulating system, they estimated that it would cost about $2 million. They believe that this option, which is being considered by the board, uses all available resources in the community to provide the maximum amount of available transportation. Of course they mentioned the need to look at training, insurance and accessibility of the vehicles. They emphasized that RTC is looking for any available partnerships to leverage everyone's resources and even volunteers such as using 211 through the United Way as part of this coordination of volunteers.