

SUMMARY OF NEEDS ASSESSMENT FINDINGS 2013 CAREGIVER SUPPORT

This report provides context for implementing caregiver support programming in San Francisco. It provides information about:

- I. The number of family caregivers in San Francisco
- II. Overall caregiver demographics
- III. Unique qualities of San Francisco's caregiver population
- IV. Common caregiver challenges
- V. Frequently-cited needs for caregiver support
- VI. Existing services in San Francisco
- VII. Estimates of unmet need for caregiver support services

I. Estimating the Number of Caregivers in San Francisco

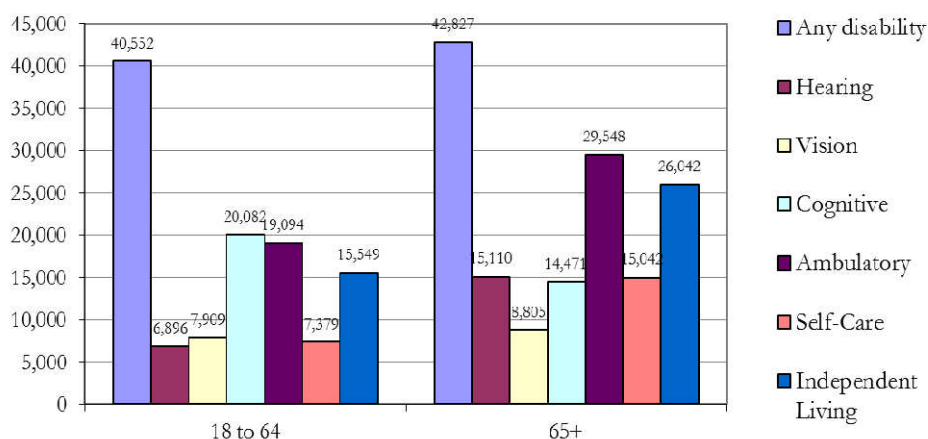
Precise caregiver statistics are unavailable for San Francisco County, especially when it comes to caregivers providing support to adults or seniors.

Disability & Dementia Statistics Estimate the Number of People that Might Rely on Family Caregivers

Disability statistics may help estimate the size of the population that may need caregiving. This chart shows 2011 estimates of the number of San Francisco residents with a variety of disabilities by age.¹ While some of these individuals may not have or need support from a family caregiver, these figures provide a sense of scale for the population that may rely on that type of support.

Furthermore, a recent report written for the San Francisco Department of Aging and Adult Services (DAAS)

San Francisco Disability Population Estimates by Age
Source: American Community Survey (ACS) 2011 3-yr estimates



Disability-Related Questions:

Hearing - Is this person deaf or does he/she have serious difficulty hearing?

Vision - Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

Cognitive - Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

Mobility - Does this person have serious difficulty walking or climbing stairs?

Self-Care - Does this person have difficult dressing or bathing?

Independence - Because of a physical, mental, or emotional condition, does this person have serious difficulty doing errands alone such as visiting a doctor's office or shopping?

¹ Disability is self-reported in the American Community Survey, and respondents may have more than disability. Note that the American Community Survey has continued to implement changes in the way that it asks questions about disability status. For that reason, these disability statistics cannot be compared exactly to those reported by the Census Bureau before 2007.

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estimated that San Francisco would be home to more than 23,000 seniors living with Alzheimer's or a related dementia in San Francisco in 2010 (Alzheimer's/Dementia Expert Panel, 2009).

National, State, and Local Studies Provide a Range of Prevalence Rates for Caregiving

The 2011 American Community Survey estimates that approximately 2,000 grandparents age 60 or older in San Francisco were responsible for their own minor grandchildren. These estimates are slightly lower than in previous years. Grandparents raising grandchildren are significantly more likely to be unmarried and to be living in poverty than other grandparents (Minkler, 2003). San Francisco's child welfare policies emphasize placing children with relatives rather than in group homes or institutions. Thirty-nine percent of foster children live with relatives in San Francisco placements as of October 2013. While this policy supports family bonds, and San Francisco does target some services for these families, it often places an enormous amount of stress and responsibility on aging aunts, uncles, and grandparents.

Reliable local estimates of the number of caregivers helping adults and seniors is more difficult to find. The definition of the term "caregiver" and size of the populations measured vary significantly across local, state, and national studies. Applying the state and nationwide percentages found in these studies to a city as unique as San Francisco yields potentially useful but statistically uncertain results. San Francisco-specific studies are limited to a single study conducted in 1999.

A 2003 study profiling California caregivers reports that 16 percent of households in California have at least one caregiver for someone age 50 or over (Scharlach). National estimates of the size of the caregiver population show similar rates. A 2009 survey of caregivers in the United States estimated that 21 percent of respondents provided unpaid care to an adult age 18 or older in the past year. Specifically, 18.9% of respondents were predominately caregivers to older adults. **If these rates hold true in San Francisco, then the number of caregivers to older adults in San Francisco would be approximately 132,000.**² Comparing these estimates to the disability figures above suggests that many adult and senior care recipients may have more than one caregiver. The 2009 California Health Interview Survey shows lower estimates: 114,000 adults in San Francisco provided care to a family member or friend of any age with an illness of disability. It seems that the true figure may be even higher, given that San Francisco has a relatively large population of seniors when compared to state or national trends. However, the 1999 study "Coming of Age in San Francisco" provided much lower estimates of the number of caregivers (27,000), but only considered older San Franciscans (age 55+) who were caregivers of others aged 55 and older.³ Given these variations, this report uses the 114,000 figure as a "middle-of-the-road" estimate.

II. Overall Caregiver Demographics

"Caregiving in California," "Caregiving in the US," and "Stressed and Strapped: Caregivers in California," published in 2006, 2004, and 2009 respectively, provide excellent profiles of the caregiver population. The following table summarizes key characteristics of individuals with

² (ACS 2011 3-yr: Population SF 18+)(.18) = estimated # of caregivers = (703,508)(.18) = 132,963

³ "Coming of Age in San Francisco" reports 16.4 percent of San Francisco's population 55 and over to be caregivers (n=500), and 25.3 percent of those providing care desiring more emotional support or respite services (n=77).

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caregiving responsibilities as found in those studies, as well as local statistics for San Francisco based on the California Health Interview Survey.

Characteristics of Caregivers of Older Adults (50+)				
	California Caregivers of Older Adults (50+)*	United States Caregivers of Older Adults (50+)**	California All Caregivers***	San Francisco All Caregivers****
Age	Average = 51	<Not listed>	18 to 44: 47% 45 to 64: 42% 65+: 11%	18 to 44: 53% 45 to 64: 39% 65+: 8%
Female	63%	67%	57%	62%
Married/Living with Partner	63%	64%	60%	39%
Employed Full-Time/Part-Time	35% / 14%	50% / 11%	52%/11%	57%/10%
High School Education or Less	32%	27%	37%	13% (results unstable)
Non-White Race/Ethnicity	39%	24%	48%***	49%

* Scharlach, 2006

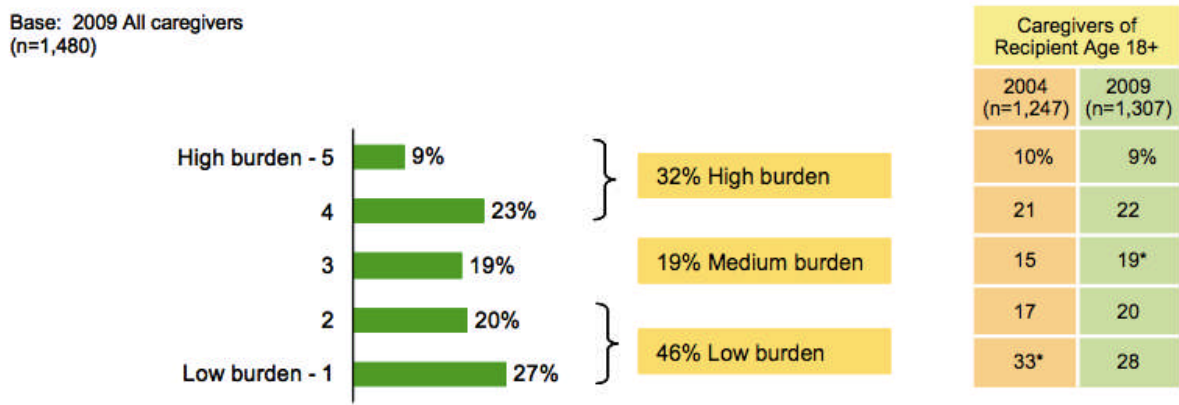
** National Alliance for Caregiving and AARP, 2009

*** Hoffman & Mendez-Luck, 2011

**** ask.chis.ucla.edu – 2009 California Health Interview Survey

Caregivers provide varying levels of support to care recipients. The National Alliance for Caregiving and AARP have developed a Level of Burden index that is derived from the amount of time caregivers spend per week helping a care recipient and the number/types of activities performed for the care recipient. The chart below shows the breakdown of level of burden across all caregivers nationally, where Level 1 is the lowest burden and Level 5 is the highest. Compared to the same survey conducted in 2004, more caregivers reported medium to high levels of burden of care.

Figure 21: Level of Care Index



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If these trends are mirrored in San Francisco, then approximately **10,260** people would be Level 5 caregivers for older adults.⁴

The report finds that high burden caregivers are more likely to say they experience physical strain, emotional stress, financial, and other hardships. This population is therefore the most likely to need intensive caregiver support services.

III. Unique Qualities of San Francisco's Caregiver Population

San Francisco is home to one of the most diverse caregiving populations in the nation, including both sizeable populations of non-English speaking people from numerous ethnicities as well as vulnerable groups such as LGBT seniors. Although much of the national and state level research profiling caregivers and their general needs also apply to the county, San Francisco's numerous linguistic, cultural, and other subgroup caregivers report unique challenges in addition to those apparent in the state or nationwide.

Ethnic Minorities. According to a UC Berkeley Study, Asians and Latinos are much less likely to seek and access caregiver support services (Scharlach, 2003). In one local focus group of Latino participants, all of the participants knew one or more Latino caregivers who needed caregiver support assistance. However, none of the caregivers had accessed caregiver support services available. This lack of service utilization often stems from a lack of knowledge about available services, but it is also the result of cultural and linguistic barriers. In some cases, ethnic minorities are reluctant to seek available services because of past experiences of insensitivity, harassment, or discrimination. Some Japanese seniors, for instance, are wary of seeking services from government institutions due to past experiences of imprisonment in internment camps during World War II (Sawamura, personal interview, July 28, 2006).

The 2006 DAAS Community Needs Assessment focus group participants stressed eroding familism as a significant family caregiving concern. Ethnic minorities are often perceived as having tight-knit families with strong supportive networks. Although many children of immigrants continue to honor family caregiving traditions, Latino and API focus group participants noted that as successive generations of immigrant families have become more educated, affluent, and acculturated, they are less likely to hold to their culture's traditional family values and expected roles. They are also more likely to be geographically dispersed, often moving away from their families because of advanced schooling or jobs or affordable housing. In a roundtable discussion with Asian and Pacific Islander service providers (July 19, 2006), many participants noted shifting attitudes about traditional Asian perceptions of family obligations and caregiving for elders, citing evictions of Chinese elders in Chinatown by younger family members. As one participant stated: "What are the traditions of Asian Americans? Are we supposed to take care of our parents? I don't know anymore."

Statewide research conducted by UC Berkeley's Center for the Advanced Study of Aging Services reinforces findings from local needs assessment activities. The Center organized racial-specific and ethnic-specific focus groups to examine cultural variations in the family caregiving experience and identify factors contributing to decisions about the use of caregiver support services. The center

⁴ Uses the estimate of 112,000 caregivers for older adults in San Francisco.

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found that “ideas about family responsibility held by members of these groups resulted in the belief that caregiving is a duty rather than a choice,” leading to more positive perceptions of caregiving. “The well-being of the care recipient [...] transcended the personal demands experienced by the individual caregiver.” However, many groups expressed concern that “cultural norms were weakening” (Scharlach, 2006).

The Lesbian, Bisexual, Gay, and Transgender Community. According to the Family Caregiver Alliance, 50 percent of LGBT individuals receiving in-home or institutional care experience discrimination or harassment from their caregivers. LGBT caregivers of older adults provide on average 48.5 hours of direct care per week and many do not utilize any outside resources for assistance, in some cases for fear of harassment or discrimination by a community provider. Almost half of LGBT caregivers serving seniors have experienced LGBT insensitivity, discrimination, or harassment from a community program (SF HRC, 2003). A recent national survey of LGBT baby boomers found that one in four respondents had provided care for an adult friend or family member in the last six months (MetLife, et. al., 2006). The same study found that equal proportions of men and women were caregivers in their survey population. While partners certainly care for one another, many local LGBT focus group participants have expressed concern and fear about needing care in the future: “Most of us don’t have children. How are we going to get the care we need when we need it?” Many LGBT seniors have transplanted to San Francisco and have fragile or few connections to family. Moreover, as one focus group participant stated: “many gays are severely independent” and consequently reluctant to accept or request care and support.

A survey of LGBT older adults in San Francisco conducted this year found that ten percent of respondents needed caregiver support, with higher rates for bisexual and transgender respondents. Of those reporting a need for caregiver support services, 27 percent were not using them, typically because they found the services difficult to access, they thought they would not qualify, or other reasons. Rates of need for caregiver support services were especially high for LGBT Asian American participants (Fredericksen-Goldsen, 2013).

IV. Common Caregiver Challenges

Informal caregivers often experience common challenges associated with their caregiving roles, including:

Financial strain. Because of their caregiving duties, many caregivers lose wages due to reduced work hours, time out of the workforce, family leave, or early retirement (Feinberg et al, 2011). Fifteen percent of California caregivers report high levels of financial hardship (Scharlach, 2003); a more recent national study found that more than one in four caregivers of adults reported a moderate to high degree of financial hardship as a result of caregiving (NAC & AARP, 2009). Estimates of lost wages and retirement benefits range from \$283,716 to \$659,130 over a lifetime (Feinberg et al, 2011; MetLife et al., 1997). This is especially burdensome for caregivers who had lower incomes at the outset. Financial impact appears to be worse for women than for men. Furthermore, many caregivers contribute out-of-pocket to the care of the care recipient. A 2004 national study estimates that caregivers spend an average of approximately \$200 in a typical month, excluding people who provided care for a spouse. A phone survey conducted in 2007 estimated costs closer to \$460 per month in caregiving-related expenses for all types of caregivers (NAC and AARP, 2004; NAC and Evercare, 2007).

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Stress. A 1999 Commission on the Aging study, “Coming of Age in San Francisco,” reports that 22 percent of San Francisco caregivers find their caregiving duties physically “stressful” or “very stressful.” Roughly one quarter found the emotional stress in providing care to another person to be “stressful or very stressful.” A national study shows higher estimates of caregivers experiencing emotional strain: nearly one third (31%) of caregivers said taking care of the person they help rates a four or five on a five point scale where five is “very stressful” (NAC and AARP, 2009). More than one fifth of California caregivers have no one they can go to for support and understanding (Scharlach, 2003). Forty-four percent of caregivers assist someone who has mental health, emotional, or behavioral problems. Caregivers of seniors with dementia or mental incapacities are particularly at risk for burnout and other negative side effects.

Health issues. Twenty-eight percent of California caregivers report health or emotional problems, including depression, anxiety, anger, and guilt. State and national studies estimate the percentage of caregivers who report having fair or poor health to be approximately 17 percent, which is much higher than the average for the entire US population (9%) (Scharlach, 2003; NAC and AARP, 2009).

V. Frequently-Cited Needs for Caregiver Support Services

National and statewide research, along with local focus groups and key informant interviews, consistently reports the need for the following types of caregiver support services:

Increased information and assistive services. Disseminating information about caregiving is a cost-effective intervention that prevents or delays more expensive long-term care. However, lack of knowledge about available services and how to access them is frequently cited as the major reason caregivers do not use services. Native English-speaking consumers often report that information about available services is difficult to navigate. Monolingual consumers found it virtually impossible to learn about and access services without outside help, typically from friends or family.

Caregiving training. Without the requisite caregiving skills, some caregivers may be unnecessarily strained – physically or mentally – and the caregivers and care recipients may be at risk for burnout or harm. As one report states: “Changes in our health care delivery system have sent relatives home from the hospital ‘sicker and quicker”” (Feinberg, 2005). However, many caregivers do not have the adequate medical training to perform activities such as operating medical equipment, monitoring and regulating medication for care recipients, and wound care. Better training, including care planning, best practices, and caregiver assessment and feedback would reduce the stress of the most at-risk caregivers and help ensure that care recipients are appropriately and safely cared for.

Respite Care. Key informants from caregiver service providers and focus group participants cited a high consumer demand for increased and more flexible provisions of subsidized respite care, including unplanned, emergency respite care, day, partial-day, in-home, institutional, and overnight care. The caregivers with the greatest unmet needs for respite care were identified as those whose incomes were too high to qualify for subsidized aid but too low to afford paid services.

Professional counseling and support groups. Caregivers are often overstressed and need emotional support, especially when they care for people with dementia, behavioral disorders, paralysis, or those who

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have suffered a stroke. San Francisco caregiver support organizations cited a need for increased individual and family professional counseling services and caregiver support groups.

Legal and financial advice. Caregivers frequently report needing legal aid regarding their rights and obligations as care providers, and information and advice on durable power of attorney for health related issues, living wills, and trusts for their care recipients. For those with lower incomes, it is especially important to have access to free or low cost services.

Culturally and linguistically appropriate services. Caregiving related attitudes, values, and behaviors vary based on caregivers' country of origin, number of years or generations in the United States, acculturation, generational status in the family, gender, and other individual characteristics. Participants from nearly all needs assessment focus groups – African-American, Latino, LGBT, Asian and Pacific Islander, and case managers – stressed the need for multi-lingual and culturally competent service workers that are able to cook traditional meals and speak the language of the care recipient.

VI. Existing Services in San Francisco

A variety of services are currently available to support caregivers in San Francisco. The National Family Caregiver Support Program, In-Home Supportive Services Program, Adult Day Programs, and Caregiver Volunteer Recruitment are described below.

As of FY 2013-2014, the Office on the Aging contracts with Family Caregiver Alliance (FCA) to offer the following constellation of services funded by the **National Family Caregiver Support Program**

- **Community Education:** A total of 29 activities specifically designed to educate current or potential caregivers.
- **Service Information:** A total of 653 units of Access Assistance, which includes outreach, information and assistance and translation services.
- **Caregiver Support:** A total of 2,589 units of support services, which include caregiver assessment, caregiver counseling, caregiver support group, caregiver training and case management.
- **Respite:** A total of 2,595 units of Respite Service, which provides intermittent, occasional, and emergency respite to caregivers, in terms of home personal care, out of home day care, or overnight care.
- **Supplemental Services:** A total of 116 Occurrence of supplemental services, which include assistive devices, caregiver legal assistance and service registry.

FCA subcontracts with Kimochi Inc, Self-help for the Elderly, and Openhouse to meet the needs of a very diverse population in San Francisco. Openhouse is providing volunteer caregiving program to the LGBT seniors.

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The **In-Home Supportive Services Program** (IHSS) allows disabled and elderly individuals to remain at home, but it also benefits relative caregivers. It can reduce the physical toll on the caregiver of tending to the recipient's self-care needs. It can provide respite to overburdened caregivers and allow them time to run errands or relax. Providing care to a relative can be particularly demanding emotionally, and having an IHSS provider come into the house can allow a relative some "breathing room" from the constant intimacy of care. Many family caregivers themselves have disabilities or self-care needs, and the presence of an IHSS worker reduces the hazards of having one frail or disabled person providing care to another. For younger disabled persons who are living independently, having a professional IHSS provider allows them more control over their lives than if they were to rely only on the availability of family members for their care. The San Francisco IHSS program provides services to more than 21,000 recipients.

IHSS can also offset the financial strain of care-giving duties. Sixty-six percent of providers (nearly 18,600) provide services to a relative. Depending on IHSS for household income, however, creates its own dilemmas. Though relatives may not have the proper training or skills or temperament, recipients may be compelled to use them as their providers out of financial necessity. If the relative care provider is also working outside of the home, then chores are more likely to be performed at the convenience of the caregiver, not the client. For the recipient, the financial necessity of hiring a relative to provide care may make supervision much more sensitive (Chung, personal interview, July 28, 2006). Chinese IHSS clients are much more likely to utilize relative caregivers.

Adult Day Programs provide a needed break for caregivers by offering social and therapeutic services for individuals with chronic illnesses.⁵ In San Francisco, these include social model adult day programs, as well as Community Based Adult Services programs (CBAS), formerly known as Adult Day Health programs. The Program for All-Inclusive Care to the Elderly (PACE) at OnLok provides adult day programming to approximately 900 additional San Francisco residents (San Francisco Human Services Agency, 2006).

DAAS also provides funding to three Alzheimers Day Care Resource Centers (ADCRC), formerly a state funded program. The ADCRCs are operated in the Adult Day Services of Institute of Aging, and Kimochi Inc., and the CBAS of Self-Help for the Elderly. The purpose of ADCRC is to assist individuals with Alzheimer's and related dementia to function at the highest possible level; to provide respite care for families and caregivers; to assist caregivers by providing information, counseling, and care planning; to establish and/or assist support groups; to train students, professionals, and caregivers; and to disseminate information to families, caregivers, professionals, and the public about Alzheimer's disease and related disorders.

VII. Estimates of the Scale of Unmet Need for Caregiver Support Services

Comparing caregiver population estimates with the scale of existing services reveals significant gaps. Even if all of the services described above are utilized by distinct caregivers, only about 13 percent of San Francisco's caregivers would be receiving any of those supports. A survey of California caregivers estimated that almost 20 percent of caregivers of older adults had never used a caregiver

⁵ There are several types of adult day programs: Adult Day Health Care (medical model), Adult Day Programs (social model), and Alzheimier's Day Care Resource Centers (specialized for participants with dementia). Most centers in San Francisco are Medi-Cal reimbursable and use a sliding scale per diem fee structure for private pay.

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support service, and two-thirds of caregivers were not receiving at least one of the types of service they believed they needed. In addition, one-third of caregivers continued to identify barriers to service use (Scharlach, 2006).

The chart on the next page uses statewide unmet need statistics in order to extrapolate *rough estimates* of the number of San Francisco caregivers of older adults who (a) do not receive formal support services and (b) still have unmet needs for each of a variety of caregiver supports. These estimates should be used to provide a sense of scale and relative size for unmet needs, not as point estimates; San Francisco's caregiver population and available services may differ in significant ways from the state.

Unmet Needs of Caregivers of Older Adults (50+) Who Did Not Receive Formal Services Source: Scharlach, 2006		San Francisco Estimates
Assistance to Caregiver	Unmet Need*	Rough Estimate of SF Caregivers of Older Adults (50+) Without Formal Services and With this Unmet Need**
Legal Information	69%	14,200
Financial Information	61%	12,500
Information about community services	60%	12,300
Help in accessing community services	54%	11,100
Education or training	47%	9,600
In-home respite	41%	8,400
Peer support group	41%	8,400
Professional counseling	35%	7,200
Day respite	32%	6,600
Overnight respite	28%	5,700
Advice/Counseling from a clergy person	23%	4,700

*Answered "yes" to "Do you think this service would be helpful?"

**Uses 114,000 as approximate estimate of SF caregivers of older adults, assumes that 18% do not use formal services (Scharlach, 2006). Figures are rounded to the nearest 100.

Note: Caregivers may have more than one unmet need.

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The following focus groups were conducted as a part of the 2006 DAAS Community Needs Assessment. Caregiver support issues were a part of many of these discussions.

Focus Groups – Consumers

- Latino Seniors, June 30, 2006.
- LGBT Seniors, June 29, 2006.
- LGBT Focus Group (Caregivers), New Leaf Services, August 12, 2006.
- Raman Hotel Residents Focus Group, Raman Hotel, June 28, 2006.
- Visitacion Valley Chinese Seniors Focus Group, Visitacion Valley Community Center, August 22, 2006.

Focus Groups – Providers

- African American Partnership, June 29, 2006.
- Asian/Pacific Islander Partnership, July 19, 2006.
- Latino Partnership, July 10, 2006.
- LeNain Hotel Case Managers, February 10, 2005.
- LGBT Partnership, June 14, 2006.
- Peer Advocates, June 23, 2006.
- Case Managers (MSSP, Linkages, Curry Senior Center), June 27, 2006.