

# Examining Availability and Need for Caregiver Support Services in Santa Clara County

Prepared for the Aging Services Collaborative  
Santa Clara County

by

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## **Abstract**

This research examined the scope and range of existing services offered to caregivers by various agencies in Santa Clara County. The goal of this project was to develop a profile of caregiver support services that are available in Santa Clara County and to identify challenges experienced by service provider agencies. The nature and extent of currently available caregiver services were assessed through an online survey whereas a focus group approach was used to understand challenges experienced by service providers in meeting caregivers' needs and to generate possible solutions to address those challenges. A purposive sample of 37 representatives of various social services agencies in Santa Clara was solicited for participation in the online survey (15 agencies completed the survey), and a convenience sample of 10 representatives who participated in the online survey was invited to participate in the focus group. Although the findings from this study were helpful in providing a profile of caregiver services offered, there were a number of agencies who did not participate in the survey, thus limiting the generalizability of the findings. Additional research that can help fill these gaps in knowledge will be useful in developing a more complete profile of caregiver services in Santa Clara County.

## **Executive Summary**

### **Introduction**

By 2020, the older adult population aged 65 and over in Santa Clara County is expected to nearly double, reaching almost 300,000. Currently, 80% of long term care in Santa Clara County is provided by a family member and the growing older population will bring an increasing need and demand for services to assist family caregivers. This study was undertaken to develop a profile of the scope and range of services currently offered to caregivers of older adults by various agencies in Santa Clara County.

### **Background**

To support family caregivers of older individuals with disabilities various caregiver support services have been created by the National Family Caregiver Support Program (NFCSP) under the Older American Act Amendments of 2000, (Family Caregiver Alliance/National Center on Caregiving, 2002). The NFCSP is authorized under the Older Americans Act and is administered by the Administration on Aging (AoA). The AoA provides State Units on Aging (SUAs) with Title III-E formula grants to work in partnership with local Area Agencies on Aging (AAAs), faith-based services, and community service providers.

Funding for five support service areas is identified in the NFCSP: 1) information to caregivers about available services and referrals; 2) assistance to caregivers in gaining access to supportive services; 3) individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiver roles; 4) respite care to temporarily relieve caregivers from their responsibilities; 5) supplemental services, on a limited basis, to complement the care provided by caregivers.

The NFCSP is being implemented in a manner that provides significant flexibility to each state which however, has resulted in a highly inconsistent range of services that vary by locality (Feinberg, Newman, & Van Steenberg, 2002). The diversity in funding sources and in the types of agencies that offer caregiver services at the local level necessitates a localized study to understand the scope and range of caregiver services provided in a particular geographic area. Thus, this study was undertaken to a) describe the range of caregiver services available to informal caregivers of older adults in Santa Clara County; b) identify unmet needs and barriers to the delivery of caregiver support services; and c) generate possible solutions that mitigate these barriers.

### **Study Methods**

A mixed methods approach was used to collect information through an online survey and a focus group. The characteristics of currently available caregiver services, client characteristics, and perceived unmet needs were examined through the online

survey whereas a focus group was used to examine challenges experienced by providers in meeting caregivers' needs and possible solutions to those challenges.

A purposive sample of 37 representatives of various social services agencies in Santa Clara was recruited for the online survey, and a convenience sample of 10 representatives who participated in the online survey were invited to participate in the focus group. Fifteen of the 37 agencies participated in the online survey (response rate = 41%), whereas 8 of the 10 invited agency representatives participated in the focus group.

The sampling frame was developed by creating a list of organizations that offered support for caregivers in Santa Clara County. The sources used to create this list included the Council on Aging's Senior Services directory and an online senior services agency directory in Santa Clara County. Through these directories, 37 agencies were identified by the ASC's Caregiver Support Team as providers of caregiver support services and were invited to participate in the online survey. The bases for including agencies in the sample were:

- 1) Agencies that were known widely and advertised that they provided caregiver services
- 2) Agencies that were known to have large numbers of caregivers served
- 3) All agencies that had adult day programs
- 4) Senior centers that were known to the committee to have strong case management programs geared towards caregivers
- 5) A few large, well-established home care agencies

Organizations that were specifically not included in the sample were:

- 1) Major hospitals that were not specifically providing caregiver services
- 2) Senior centers that were not known as providers of caregiver support services
- 3) The majority of home care agencies that were not known as providers of caregiver services

The 10 participants for the focus group were chosen based on recommendations from the Aging Services Collaborative (ASC) team and the sample consisted of a mix of agencies in terms of their organizational type and size.

## Key Findings

**Online Survey:** Based on the data provided by the 15 participating agencies, the key findings of the online survey are as follows:

1. **Types of Organizations offering Caregiver Services:** Caregiver services in Santa Clara County are offered by various types of non-profit organizations, not all of which receive Title III E funding for their caregiver support services. (Table 1).
2. **Geographic Areas Served:** Sixty-seven percent of the participating agencies deliver their services to all 16 cities in Santa Clara County.

3. **Agency Referral Sources:** The most common referral sources for the agencies' services were word of mouth and medical providers, followed by other agencies. Websites were less commonly cited as information referral sources, although the majority of agencies advertise their caregiver support services through their website. Thus, both informal and formal marketing of caregiver services is an important way to increase awareness of available services. (Table 2).
4. **Language Service Capacity and Client Ethnicity:** Of the 14 agencies that responded, ten provided racial and ethnic information on their caregiver clients. Among the total clients served by these ten agencies, there are eight agencies where 50% or more of their clients are White/Caucasian (range from 50% to 90%). Service capacity in Spanish was available in 67% of the participating agencies, yet 93% of the agencies reported serving Hispanic/Latino caregivers, with the percentage of such clients served by these agencies ranging from 2% to 24%. Similarly, although roughly one quarter to a third of the agencies reported capacity in one or more Asian languages (Mandarin, Vietnamese, Cantonese, and Japanese) all agencies reported serving Asian caregivers. The percentage range of Black/African American caregivers served by these agencies was 1% to 10%. The percentages for Native Hawaiian/Pacific Islander caregivers ranged from 0% to 13%; and for Alaska Native/Native Americans from 0% to 2%. Not all caregivers of different ethnicities require services in languages other than English. Most of the agencies did not note language capacity as one of the important barriers to service delivery, rather it was the cultural background of the client that was noted as a significant barrier that prevented caregivers from receiving the support they need (see item 10 below). (Tables 3 & 4).
5. **Caregiver Needs & Unmet Needs:** The participants were asked to rank the top three needs of caregivers. Among the 11 agencies responding to this question, emotional support was noted as the number one need for their caregivers followed by respite and in-home support. Agencies ranked respite service, affordable/low cost case management, and financial assistance as the top unmet needs for which they were unable to deliver services to caregivers. (Table 5).
6. **Caregiver Services Provided:** Except for information and assistance which is provided by all agencies in the sample, caregiver services in each NFCSP service category are not consistently provided across agencies. The other most commonly provided services across the sample were: Assessment (73%); Training and Education (67%); Counseling (67%); Respite (60%); Case Management (53%); and Caregiver support group (47%). (Table 6).
7. **Number of Caregivers Served:** Data on the number of caregivers served by each agency was substantially incomplete as many respondents either did not have these data or did not provide them. The most complete data reported on number of caregivers served were for Information & Assistance (a combined total of 17,186 clients served by 14 agencies) and for any Respite service (a combined total of 430 clients served by all 9 agencies who provided this service). (Tables 7 & 8). Thus, among these 15 agencies a fairly small number of caregivers receive any respite services.

8. **Variations in Service Provision by Funding Source:** Differences in services provided between Title III E funded agencies and non-Title III E recipients were observed. Information and Assistance services were provided by all agencies. Whereas respite services were provided by all Title III E recipient agencies, less than half of the non-Title III E recipient agencies provided respite services. Differences were also observed in the provision of case management and support groups for caregivers with non-Title III E funding recipients being less likely to provide these services. (Table 9).
9. **Engaging Volunteers:** A large proportion of participating agencies (73%) rely on volunteer staff directly and indirectly to deliver various services to caregivers. The majority of agencies are interested in engaging well-trained volunteer staff, and almost two-thirds were somewhat or very likely to use a well-formed volunteer training curriculum if one were available.
10. **Barriers to Service Delivery:** Financial status of the caregiver was cited by 71% of the agencies as the most common barrier that prevented caregivers from receiving the support they need. Thirty-six percent of the agencies noted the caregiver's geographic location as a reason for ineligibility for receiving caregiver services (these agencies did not operate in every city in the county). Other barriers included lack of staff familiarity with community resources, lack of awareness among caregivers and community, lack of transportation, and lack of outreach. Five agencies (36%) indicated that cultural differences (of the clients) were the barrier to service delivery.
11. **Reductions in Service Provision:** Six (43%) of the agencies noted reductions in caregiver services provided during fiscal year 2009 and 2010 primarily due to loss of funding. The areas of services reduced were intake, caregiver training and workshops, respite service, group counseling and coaching, and socialization services.

**Focus Group:** Based on the data provided by the 8 participants, the key findings of the focus group discussion are as follows:

1. **Problems experienced in Service Delivery.** The common themes that emerged related to this issue are:
- i. *Cultural Barriers* such as language capacity and cultural customs were identified by participants as a challenge to service delivery.
  - ii. *Lack of Funding* was described as a reason many programs and services are unable to begin or to be maintained. A participant indicated that because family caregiver funding from the federal level was a fairly recent development, it was still in the start up and coordination phase. The current funding system has not allowed agencies to collaborate with each other and forces each agency to create duplicate services that are provided by other agencies.
  - iii. *Lack of Collaboration* among service providers was identified as a service delivery problem.
  - iv. *Difficulty in Reaching Older Spousal Caregivers* was also noted by providers. It

was especially difficult to reach out to caregivers for homebound seniors, since they are unlikely to be connected with any services and they tend not to identify themselves as caregivers. This phenomenon was often seen among ethnic groups and among older spousal caregivers who have less of a support system.

**2. Possible Solutions to Address Service Delivery Issues.** The common themes in the responses to this question are as follows:

- i. *Engagement of Volunteers* was discussed as an important solution to many problems, although there were some challenges associated with it. Participants agreed that engaging volunteers would be beneficial and would address many of their service delivery problems. However, most believed that it would be very difficult to develop a volunteer program within their agency, due to limited staffing resources, lack of time, and limited funding.
- ii. *Outreach and Education* is particularly important to reach out to caregivers from different cultural and ethnic communities. Many agencies have been investing their efforts into outreach and education to reach out to caregivers in their community.
- iii. *Collaboration among Agencies* such as sharing a pool of volunteers might be useful. Participants noted that coordinating with other agencies would help fill in the gaps for clients. A client database, where every agency is connected, would be useful in preventing duplication of services.

### **Concluding Observations**

This study describes the diversity of caregiver services that exist in Santa Clara County and provides information on the numbers of caregivers served through Information and Assistance and Respite services; agency capacity to provide services in languages other than English; providers' perceptions of caregiver needs and unmet needs; and agencies' interest in engaging trained volunteers to enhance service provision. Additionally, it also highlights some of the common problems experienced by service providers, and some possible solutions that may mitigate these problems. Some caveats to these findings include the response rate on the survey (41%) and the single focus group which limits the generalizability of the study.

Additional research in specific areas can provide a better picture of existing caregiver support services in Santa Clara County. For example, data on numbers of caregivers who are provided various services through Title III E funds may be obtainable through other sources such as annual reports submitted to the Council on Aging. This will not be the case, however, for agencies not funded by Title III E. Future surveys should be shorter in length and complexity, and alternatives to caregiver service hours be considered as measures of service delivery as many agencies did not have this information available.

Additional focus groups could be conducted to capture the experiences of a larger

number and variety of service providers. This could include non-traditional service providers such as ethnic and cultural organizations and places of worship which may have very different access to the community as compared to social services organizations. Finally, an examination of the state of caregiver support agencies in other geographic areas with similar demographics might provide useful insights for addressing the needs of diverse caregivers.

## **Introduction**

Increased longevity is one of the greatest achievements of the 20th century. By 2030 there will be about 71.5 million older persons in the United States, more than twice their number in 2000, and will represent 20% of the population. The number of individuals 85 years and over is expected to more than double by 2030, and minority populations are projected to represent 26% of the older population in 2030, up from 17% in 2002 (Federal Interagency Forum on Aging Statistics, 2011).

Because of this demographic shift to an increasingly older society, the incidence of family caregiving will also increase, and unpaid family caregivers (the largest source of long-term care services in the U.S.) are estimated to reach 37 million caregivers by 2050, an increase of 85% from 2000 (Family Caregiver Alliance, 2005). Family caregivers provide care for aging parents, siblings, and friends, most of whom have one or more chronic conditions and who wish to remain in their own homes and communities as they age (Family Caregiver Alliance, 2009).

Santa Clara County has seen an increase in the older adult population, as well. By 2020, the older adult population over 65 in Santa Clara County is expected to nearly double, reaching almost 300,000. Currently, 80% of long term care in Santa Clara County is provided by a family member (The Health Trust, 2010).

### *The National Family Caregiver Support Program*

In order to provide support to family caregivers of older individuals with disabilities various caregiver support services have been created by the National Family Caregiver Support Program (NFCSP) under the Older American Act Amendments of 2000, (Family Caregiver Alliance/National Center on Caregiving, 2002).

The NFCSP is authorized under the Older Americans Act and is administered by the Administration on Aging (AoA). The AoA provides State Units on Aging (SUAs) with Title III-E formula grants to work in partnership with local Area Agencies on Aging (AAAs), faith-based services, and community service providers. These grants provide funding for five support service areas identified in the NFCSP: 1) information to caregivers about available services and referrals; 2) assistance to caregivers in gaining access to supportive services; 3) individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiver roles; 4) respite care to temporarily relieve caregivers from their responsibilities; 5) supplemental services, on a limited basis, to complement the care provided by caregivers.

As evidenced by the passage of the NFCSP in 2000, the federal government is playing an increasingly important role in supporting family caregivers of older persons. However, states have led the way in designing and financing strategies to help families in their caregiver roles. States have generally supported and sustained caregiver families through four main strategies: 1) direct services, 2) financial compensation, including direct

payments or vouchers that promote consumer direction and let caregivers choose goods and/or services, 3) tax incentives, and 4) family leave policies (Greene & Feinberg, 1999).

The NFCSP is being implemented in a manner that provides significant flexibility to each state (Feinberg, Newman, & Van Steenberg, 2002). Preliminary state NFCSP implementation plans and policies for funding programs vary in the range and scope of Title III-E support services provided. However, most states emphasize respite and supplemental services while some states have integrated caregiver support into their home- and community-based service (HCBS) systems (Coleman & Dize, 2002).

This flexibility in implementation has promoted a variety of service options that might paradoxically limit, rather than enhance, choices for family caregivers (Feinberg et al., 2002). According to Feinberg and colleagues, states face a difficult balancing act: giving Area Aging Agencies (AAAs) local flexibility that encourage individualized options to meeting caregiver needs, while simultaneously setting statewide standards so that family caregivers can access a core set of caregiver support services and service delivery options regardless of where they live. In general, the balance has tipped towards local flexibility, resulting in a highly inconsistent range of services, varying by locality.

### *Overview of California's Caregiver Support System*

The information provided in this section is from Feinberg, Newman & Van Steenberg (2002). Many of California's publicly funded programs providing caregiver support predate the passage of the NFCSP under the Older Americans Act Amendments of 2000 (Feinberg et al., 2002). The most significant program is the state-funded Caregiver Resource Center (CRC) system administered by the Department of Mental Health (DMH). With the passage of the NFCSP under the Older Americans Act, another state department, the California Department of Aging (CDA), began administering caregiver support services with federal NFCSP dollars. Thus, the CDA and the DMH both administer programs that support caregivers directly. The DMH's Caregiver Resource Center focuses on caregivers of individuals, over 18 years of age, with adult-onset brain diseases/disorders and dementia and operates through 11 contracts with nonprofit agencies to deliver a wide array of services. The California Department of Aging's NFCSP, consistent with Administration on Aging (AoA) guidelines, serves a more broadly defined population, that is, individuals aged 60 years or more with any diagnosis, or those under 60 years with a diagnosis of cognitive impairment. The CDA provides funding via a formula to the state's 33 Area Agencies on Aging (AAA), and in turn, the AAA's either provide caregiver support services directly or subcontract with service providers in the local community. Family caregivers also benefit indirectly through several other CDA programs such as the In-Home Support Services (IHSS) program administered by the Department of Social Services. Significant CDA programs that assist family and informal caregivers are the Alzheimer's Day Care Resource Centers (ADCRC), Adult Day Health Care (ADHC), the Aged Medicaid waiver (the Multipurpose Senior Services Program, or MSSP), Linkages (a case management program), and the Senior Companion program. Because administrative responsibility for caregiver support and home and community-based services is spread across numerous state agencies in California, coordination and integration of services is a difficult task. Moreover, administrative fragmentation at the state level leads to greater fragmentation at the local

level, where family caregivers attempt to access services.

### *Caregiver Support Services in Santa Clara County*

According to the Council on Aging (COA), Silicon Valley's Area Plan on Aging for 2009-2012, approximately 24% of the 60+ population in Santa Clara County have daily caregiving responsibilities. This means that over 52,000 older persons provide some informal assistance to a family member, friend or neighbor (COA, 2009). Almost half of the recipients of informal care are spouses or partners, although older caregivers also provide such assistance to younger (children or grandchildren) as well as older generations (parents). In Santa Clara County, the COA uses Title III E monies to fund caregiver support services however, agencies also use other sources of funding for their caregiver services.

## **Purpose of this Study**

Because of the diversity in funding for caregiver services and in the types of agencies that offer such services in local areas, this study was undertaken to a) describe caregiver services available to caregivers of older adults in Santa Clara County; b) identify unmet needs and barriers to the delivery of caregiver support services; and c) generate possible solutions that mitigate these barriers.

This study collected both quantitative and qualitative data through an online survey and a focus group with service providers. The following research questions were used to guide the study: 1) What are the current caregiver support services being provided? 2) Are similar services provided to caregivers by various agencies? 3) What problems exist in delivering caregiver support services? 4) What are some potential solutions that can reduce barriers to the delivery of caregiver support services?

## **Methods**

The aims of this study were to: 1) describe and analyze trends in support services for family caregivers provided by four types of agencies: publicly funded organizations, privately funded organizations, faith-based community organizations, and organizations receiving Older Americans Act Title III-E grants in Santa Clara County; and 2) gain an understanding of areas in which delivery of services to clients could be improved as perceived by service providers.

### ***Study Design***

The study used two methods to collect data: 1) A self-administered, online survey consisting of questions related to caregiver support services provided by social services agencies (see Appendix A); and 2) A focus group was held with several providers who had

participated in the online survey to obtain in-depth information related to problems experienced in delivering services, and generating possible solutions to the problems (see Appendix B). Written consent for both studies was deemed exempt by San José State University Human Subjects-Institutional Review Board.

### ***Sample***

The sampling frame was developed by creating a list of organizations that offered support for caregivers in Santa Clara County. The sources used to create this list included the Council on Aging's Senior Services directory and an online senior services agency directory in Santa Clara County. Through these directories, 37 agencies were identified by the ASC's Caregiver Support Team as providers of caregiver support services and were invited to participate in the online survey. The bases for including agencies in the sample were:

- 1) Agencies that were known widely and advertised that they provided caregiver services
- 2) Agencies that were known to have large numbers of caregivers served
- 3) All agencies that had adult day programs
- 4) Senior centers that were known to the committee to have strong case management programs geared towards caregivers
- 5) A few large, well-established home care agencies

Organizations that were specifically not included in the sample were:

- 1) Major hospitals that were not specifically providing caregiver services
- 2) Senior centers that were not known as providers of caregiver support services
- 3) The majority of home care agencies that were not known as providers of caregiver services

The 10 participants for the focus group were chosen based on recommendations from the Aging Services Collaborative (ASC) team and the sample consisted of a mix of agencies in terms of their organizational type and size.

### ***Procedures***

Data were collected through a self-administered online survey posted on Survey Monkey. The participants were initially given two weeks to complete the online survey, but were then given another week, due to the low number of responses. Telephone calls were made directly to the agency representatives who had agreed to participate in the survey to encourage them to complete it before the survey would be closed. The online survey was sent to 37 agencies, and 17 of them (45.9%) agreed to participate. However, only 15 completed the survey. Two agencies declined to participate in the survey after opening the link to the survey.

The focus group was scheduled a couple of weeks after the online survey questionnaire was distributed. Eight staff members representing six agencies participated in the focus group: six in person and two by telephone conference.

## Findings

### *Results of the Online Survey*

The main purpose of the survey was to explore the nature of current caregiver support services provided by social services agencies in Santa Clara County to determine any trends in terms of the services offered and how these services were delivered. The results of the survey are described below. All data were from fiscal year 2009-2010.

### *Characteristics of Agencies Providing Caregiver Support Services*

Various types of agencies participated in the online survey. The agencies (N=15) who responded to the online survey identified themselves generally as adult day centers, senior centers, and care management agencies (see Table 1). Five (33.3%) agencies identified themselves as Other Type, which included agencies providing grants and funds; comprehensive social services; grief support; caregiver enrichment training; and volunteer support.

Table 1. *Type of agencies participating in the survey (N=14)*

| Agencies  | Number of Agencies | Percentage |
|---|--------------------|------------|
| Other   | 5                  | 33.3%      |
| Adult Day Center                                    | 3                  | 20.0%      |
| Care Management                                     | 1                  | 6.7%       |
| Hospice   | 1                  | 6.7%       |
| Senior Center/Community Center                      | 1                  | 6.7%       |
| Adult Day Center and Senior Center/Community Center | 1                  | 6.7%       |
| Care Management & Senior Center/Community Center    | 1                  | 6.7%       |
| Care Management Center, Home Care, and Other        | 1                  | 6.7%       |
| Care Management Center and Other                    | 1                  | 6.7%       |
| Hospital/Medical Group                              | 0                  | 0%         |
| Total   | 14                 |            |

Of the 15 agencies, 14 (93%) were non-profit organizations and only 1 (7%) was a for-profit organization. No agencies identified themselves as a faith-based community organization. Among those agencies that participated, only 4 agencies (27%) were receiving Title-III E funding for some of their caregiver support services.

### *Geographic Service Area*

Of the 15 agencies participating in the survey, ten agencies (67%) listed their service area as the entire 16 cities in Santa Clara County. A larger proportion of the participating agencies served the communities of Mountain View, Los Altos, and Sunnyvale (87%), whereas Gilroy, Milpitas, and Morgan Hill were served by 67% of the agencies in the sample.

### *Referral Sources*

Agencies reported receiving referrals for caregiver clients through various sources (see Table 2). The most common referral sources reported by 14 agencies (93.3%) were word of mouth and medical provider, followed by other community-based organization. The five agencies that selected “other” mentioned that their clients were referred by the agency’s own website, advertisements on Craigslist, schools, churches, health fairs, or through another agency’s website. The majority of agencies (73.3%) that participated in the survey advertise their services through their own website. However, agency websites were not reported as a common referral source.

Table 2. *Main Referral Sources (N=14)*

| Referral Sources                   | Number of Agencies | Percentage |
|------------------------------------|--------------------|------------|
| Word of Mouth                      | 14                 | 93.3%      |
| Medical Provider                   | 14                 | 93.3%      |
| Other Community Based Organization | 12                 | 80.0%      |
| City Agency                        | 8                  | 53.3%      |
| County Agency                      | 8                  | 53.3%      |
| Brochure                           | 8                  | 53.3%      |
| Email                              | 7                  | 46.7%      |
| Newsletter                         | 6                  | 40.0%      |
| Other                              | 5                  | 31.3%      |

### *Services Provided in Languages Other than English*

A wide variety of languages are spoken by caregivers living in Santa Clara County. Of the 15 agencies who participated in the survey, 10 agencies (67%) reported that they provided their caregiver support services in Spanish, while only one agency (7%) provided services in Korean (see Table 3). Five agencies (33%) provided their services in Mandarin and other languages including Portuguese, Hindi, and Farsi. One agency noted that 38 languages were spoken among their own team of volunteers. Two agencies mentioned that language was not an issue in service delivery. One agency answered that the need for speaking a language other than English was required infrequently. One agency answered that they offer their services in English only, but they would prefer to provide support in other languages as well.

Table 3. *Services Provided in Languages Other than English (N=15)*

| Language Available | Number of Agencies | Percentage |
|--------------------|--------------------|------------|
| Spanish            | 10                 | 67%        |
| Mandarin           | 5                  | 33%        |
| Other              | 5                  | 33%        |
| Vietnamese         | 4                  | 27%        |
| Tagalog            | 4                  | 27%        |
| Cantonese          | 3                  | 20%        |
| Japanese           | 3                  | 20%        |
| Korean             | 1                  | 7%         |

### *Racial/Ethnic Characteristics of Caregivers Served*

Unfortunately, not all agencies provided data on the ethnic/racial breakdown of their caregivers (Table 4). Of the total 15 agencies that participated in the survey, one agency left this question incomplete. Of the 14 agencies that responded, ten provided racial and ethnic information on their caregiver clients. Among the total clients served by these ten agencies, there are eight agencies where 50% or more of their clients are whites (range from 50% to 90%). Two agencies reported that the majority of their clients were Asian (80% and 48%). No agency in the sample reported serving predominantly Hispanic/Latino caregivers, with the percentage of such clients served ranging from 2% to 24%. Similarly, the percentage range of Black/African American caregivers served was 1% to 10%. The percentages for Native Hawaiian/Pacific Islanders ranged from 0% to 13%; and for Alaska Native/Native Americans ranged from 0% to 2%. It is important to note that most agencies provided estimates of the percentages of the various ethnic/racial groups among the clients they served and it is not possible to extrapolate absolute numbers of clients served in each ethnicity/race category from these data.

Table 4. *Racial/Ethnic Characteristics of Caregivers Served (N=14)*

| Agency | White (%) | Black/African Amer (%) | Asian (%) | Hispanic /Latino (%) | Alaska/ Native American (%) | Native Hawaiian/ Pac Island (%) | Other (%) | Un-known (%) |
|--------|-----------|------------------------|-----------|----------------------|-----------------------------|---------------------------------|-----------|--------------|
| I      | 62        | 1                      | 5         | 20                   | 1                           | 5                               | 5         | 1            |
| II     | 75        | 10                     | 10        | 5                    | 0                           | 0                               | 0         | 0            |
| III    | 54        | 5                      | 7         | 24                   | 0                           | 0                               | 0         | 10           |
| IV     | 64        | 5                      | 11        | 18                   | 0                           | 0                               | 2         | 0            |
| V      | 61        | 7                      | 12        | 11                   | 2                           | 4                               | 4         | 0            |
| VI     | 50        | 0                      | 30        | 20                   | 0                           | 0                               | 0         | 0            |
| VII    | 89        | 1                      | 6         | 3                    | 0                           | 1                               | 0         | 0            |
| VIII   | 15        | 0                      | 80        | 0                    | 0                           | 5                               | 0         | 0            |
| IX     | 17        | 4                      | 48        | 17                   | 0                           | 13                              | 0         | 0            |
| X      | 90        | 2                      | 5         | 2                    | 0                           | 0                               | 1         | 0            |

### *Needs of Caregivers*

The participants were asked to rank the top three needs of caregivers. One agency left the question incomplete and three agencies provided more than 3 responses. Thus, they were omitted from the data analysis ( $N=11$ ). Among the 11 remaining agencies, emotional support was listed as the number one need for their caregiver clients with 11 responses; respite and in-home support were the second most reported needs with 9 responses; and financial/benefit assistance was the third most reported need with 5 responses. One agency mentioned that transportation was one of their top three needs of caregivers.

### *Greatest Unmet Needs of Caregivers*

The agencies were asked to rank the greatest unmet needs, i.e., needs for which they were unable to deliver services to caregivers (Table 5). Two agencies left the question incomplete. Respite and affordable/low cost case management were noted the top unmet needs. Financial assistance was the third most common unmet need, followed by counseling/support and transportation. Care in rural area was least likely to be listed as an unmet need among caregivers.

Table 5. *Greatest Unmet Needs of Caregivers (N=13)*

| <b>Greatest Unmet Needs of Caregivers</b>         | <b>Total Score</b> | <b>Rank</b> |
|---|--------------------|-------------|
| Respite   | 96                 | 1           |
| Affordable/Low Cost Case Management               | 96                 | 1           |
| Financial Assistance                              | 92                 | 3           |
| Counseling/Support                                | 79                 | 4           |
| Transportation                                    | 71                 | 5           |
| Legal Consultation                                | 62                 | 6           |
| Culturally and Linguistically Appropriate Service | 57                 | 7           |
| Caregiver Group Training                          | 56                 | 8           |
| Caregiver Individual Coaching                     | 55                 | 9           |
| Caregiver Support Group                           | 51                 | 10          |
| Meal Services                                     | 45                 | 11          |
| Care in Rural Area                                | 43                 | 12          |

\*Total score was calculated as follows,

(Rank 1=10 pts, Rank 2=9 pts, Rank 3=8, Rank 4=7, Rank 5=6, Rank 6=5, Rank 7=4, Rank 8=3, Rank 9=2, Rank 10=1)

10 different responses received, thus the highest rank was assigned a score of 10.

### *Types of Caregiver Services Provided By Agencies*

There are many types of caregiver services provided by agencies in Santa Clara County (Table 6). To ensure that agencies were defining services consistently, a description was provided for each service based on the NFCSP service descriptions outlined by the California Department on Aging.

The most common caregiver service provided by all 15 agencies was Information and Assistance (100%) followed by: Assessment (73%); Training and Education (67%); Counseling (67%); Respite (60%); Case Management (53%); and Caregiver support group (47%).

Data on the number of caregivers served by each agency were substantially incomplete as many respondents either did not have these data or did not provide them. The most complete data reported on number of caregivers served were for Information & Assistance (a combined total of 17,186 clients served by 14 agencies) and for Respite service (a combined total of 430 clients served by all 9 agencies who provided this service).

Five agencies (41%) replied that they offer other services to their caregiver clients, including anticipatory grief counseling, grief care after the death of a loved one, grief

workshops, annual memorial celebrations, care management support services, caregiver related activities with other co-funding agencies, safety training and job preparedness, and caregiver conferences.

Table 6. *Types of Caregiver Services Provided By Agencies (N=15)*

| Caregiver Service            | Agencies Providing Service | Percentage of sample | Number of Caregivers Served |
|------------------------------|----------------------------|----------------------|-----------------------------|
| Information and Assistance   | 15                         | 100%                 | Total: 17,186 (N=14)        |
| Respite Service              | 9                          | 60%                  | Total: 430 (N=9)            |
| Caregiver Assessment         | 11                         | 73%                  | incomplete data             |
| Caregiver Counseling         | 10                         | 67%                  | incomplete data             |
| Caregiver Support Group      | 7                          | 47%                  | incomplete data             |
| Caregiver Training/Education | 10                         | 67%                  | incomplete data             |
| Caregiver Case Management    | 8                          | 53%                  | incomplete data             |
| Other                        | 5                          | 33%                  | incomplete data             |

#### *Type of Respite Service Provided by Agencies*

Nine agencies that participated in the survey provided respite services (Table 7). The most common was in-home respite service provided by 6 agencies (67%). Overnight Respite was the least common service, provided by only two agencies (22%)

Table 7: *Type of Respite Service Provided by Agencies (N=9)*

| Respite Service   | Agencies providing service | Percentage of Respite Providers |
|---|----------------------------|---------------------------------|
| Respite In-Home Service                                 | 6                          | 67%                             |
| Respite Adult Day Care                                  | 4                          | 44%                             |
| Respite Homemaker Assistance & Personal Care Assistance | 3                          | 33%                             |
| Respite Out-of-Home Overnight                           | 2                          | 22%                             |

#### *Additional Services Provided by Agencies*

Various additional services are provided to caregivers by agencies participating in this survey (Table 8). One agency left this survey question incomplete. Therefore, 14 agencies answered this question. Of those 14 agencies, 9 (64%) provided at least one additional caregiver support service to their clients. Both placement services and transportation were the most common additional services (56%). Next most common additional service was assistive devices, with 4 agencies (44%) providing such a service. The additional services provided by two agencies included providing disaster kits, health education, health screenings, pick-up and dispensing services for unused and/or old

medications, and pick-up and dispensing services for hazardous wastes. None provided caregiver legal assistance.

Table 8. *Additional Services Provided by Agencies (N=14)*

| Additional Service             | Agencies Providing Service | Percentage of sample |
|--------------------------------|----------------------------|----------------------|
| Transportation Assistance      | 5                          | 36%                  |
| Placement Services             | 5                          | 36%                  |
| Assistive Devices              | 4                          | 29%                  |
| Meal Prep Assistance           | 3                          | 21%                  |
| Caregiver Financial Assistance | 3                          | 21%                  |
| Other                          | 2                          | 14%                  |
| Home Adaptation Assistance     | 3                          | 20%                  |
| Caregiver Legal Assistance     | 0                          | 0%                   |

*Differences in Service Provision by Funding Source*

Some differences in services provided between Title III E funding recipient agencies and non-Title III E funding were observed (Table 9). Among fifteen agencies, 4 (27%) agencies received Title III E funding and 11 (73%) did not. Information and Assistance services were provided by all agencies. Whereas respite services were provided by all Title III E recipient agencies, less than half of the non-Title III E recipient agencies provided this. Differences in service provision by funding source were also observed in the provision of case management and support groups for caregivers, with non-Title III E funding recipients being less likely to provide these services.

Table 9. *Differences in Service Provision by Funding Source (N=15)*

| Care Services Provided by Agencies  | Receipt of Title III E Funds |           |
|-------------------------------------|------------------------------|-----------|
|                                     | Yes (n=4)                    | No (n=11) |
| Information and Assistance (n=15)   | 4 (100%)                     | 11 (100%) |
| Caregiver Assessment (n=11)         | 3 (76%)                      | 8 (73%)   |
| Caregiver Counseling (n=10)         | 2 (50%)                      | 8 (73%)   |
| Caregiver Support Group (n=7)       | 3 (76%)                      | 4 (37%)   |
| Caregiver Training/Education (n=10) | 3 (76%)                      | 7 (64%)   |
| Caregiver Case Management (n=8)     | 3 (76%)                      | 5 (46%)   |
| Respite Service (n=9)               | 4 (100%)                     | 5 (46%)   |

*Engagement of Volunteers*

Many agencies engaged volunteers to deliver services to caregivers. Of the 15 agencies, 11 (73.3%) engaged volunteer staff directly and indirectly to serve their caregiver clients. The roles of volunteers varied among agencies (i.e., information and referral, caregiver consultation, transportation, friendly visitors, palliative and end of life care, safe

at home phone call, holiday visitors, cleaning, meal preparation, information and assistance, caregiver counseling, in-home services, respite care for caregivers, survey for the needs of caregivers and data entry, assisting senior day program, caregiver volunteer coordination/program outreach).

The majority of agencies were interested in engaging well-trained volunteer staff to deliver services to caregivers. Ten (71%) out of 14 agencies replied that they would be very likely to use well-trained volunteers to assist in the delivery of caregiver services. Two agencies (14%) reported that they were somewhat likely to use a well-trained volunteer. Two agencies (14%) answered that they were not likely to use a volunteer. Six agencies (43%) were very likely to use well-formed volunteer caregiving training curriculum, if one was made available. Four agencies (29%) were somewhat likely to use the curriculum. Four agencies (29%) were unlikely to use the training curriculum.

#### *Service Delivery Barriers: Eligibility Criteria for Receiving Caregiver Services*

Eligibility criteria can be a significant problem for service delivery. Fourteen of the 15 agencies that participated in this survey answered this question. Of the 14 agencies, 5 (36%) stated that geographic location was the primary reason for caregivers being ineligible to receive the services they required. Three (21%) said that the ability to pay and the diagnosis of the care recipient were the next most common reasons. One agency reported that the level of impairment of the care recipient and language capability were primary reasons caregivers were ineligible for services. One agency reported that the primary reason for ineligibility was the age of caregiver and care recipient. No agency in the survey reported client's income as the primary reason for ineligibility. Four agencies (28.5%) stated that there was no issue with ineligibility.

#### *Other Barriers to Service Delivery*

Several other barriers exist in delivering services to caregivers. Of 14 agencies, 10 (71%) stated that financial reasons (i.e., financial status of the client or caregiver) were the most common barrier to delivering their services. Seven agencies (50%) chose other barriers, including lack of staff familiarity with community resources, lack of awareness among caregivers and community, caregiver's inability to pay for services, lack of transportation, and lack of outreach. Only five agencies (36%) indicated that cultural differences (of the client) were the barrier to service delivery. Two agencies (13%) answered that they could not identify a barrier, although they were aware that barriers to service delivery exist.

#### *Reduction in Caregiver Services Provided*

With many counties facing budget shortfalls, caregiver services are being reduced. Of the fourteen agencies responding to the question whether they had reduced caregiver services in the past year, six (43%) noted reductions in caregiver services provided during fiscal year 2009 and 2010. The primary reason for reducing their services was the loss of funding. The areas of services reduced were intake, caregiver training and workshops, respite service, group counseling and coaching, and socialization services.

## ***Summary of the Focus Group Discussion***

The purpose of focus group was to explore the personal experiences of providers serving caregivers in order to understand the problems of caregiver service delivery and to generate ideas to deliver caregiver services in a more effective manner.

The focus group meeting was recorded and transcribed, and the narratives were examined for common themes. Themes in problems of service delivery were Cultural barriers; Lack of funding; Lack of collaboration; and Difficulty in outreach to caregivers for homebound seniors. Themes for solutions proposed to address the problems of service delivery are Engaging volunteers; Outreach and education to caregivers; and Collaboration among agencies.

### ***Problems with Service Delivery***

#### *Cultural Barriers*

One common theme that emerged as a barrier to delivering services to caregivers was cultural barriers. These participants identified language barriers and cultural customs to be a challenge in service delivery. This is exemplified in the following comments:

*“There are definitely people that have language barriers and cultural customs even as basic as food where somebody coming in could deliver food which is not acceptable to the family to care for their loved one. Vendors are nice, but a lot of times they don’t know the customs of the family.”*

Another participant described ethnic populations as

*“Not quite understanding the benefits that come with all of the services available... especially in those cultural populations, there needs to be a push for education on how all parties in the family can benefit (from services).”*

#### *Lack of Funding*

Lack of funding was described as a reason many programs and services are unable to begin or to be maintained. A participant indicated that because family caregiver funding from the federal level was a fairly recent development, it was still in the start up and coordination phase. The current funding system has not allowed agencies to collaborate with each other and forces each agency to create duplicate services that are provided by other agencies. One participant mentioned,

*“Funding and money tell us how we do and what we do, and unfortunately, when we do that, we get stopped from working with each other. They don’t allow us to penetrate and everyone has to recreate (services). It’s not the best use of funding because we are all doing the same thing over and over.”*

### *Lack of Collaboration*

Lack of collaboration among service providers was identified as a service delivery problem as exemplified by this participant's response:

*"I think there is a lack of collaboration among the services within the valley...We individually sort of build around our funding and our own caregiver service. When we are trying to direct somebody, they have to restart the process with other services...it does create barriers for us in trying to locate services for people and for the caregivers because they are getting pushed from one system to another, depending on their eligibility for different things..."*

### *Difficulty in Reaching Older Spousal Caregivers*

Providers who participated in the focus group noted difficulty in reaching out to caregivers for homebound seniors, since they are unlikely to be connected with any services and they tend not to identify themselves as caregivers. Often these are older spousal caregivers who have less of a support system. Another participant noted that this phenomenon was often seen among ethnic groups. As noted by one participant:

*"They do not identify themselves as caregivers, because in the spousal role or the sibling role, that's just what they do. They don't think of themselves as being caregivers."*

### ***Possible Solutions to Address Service Delivery Issues***

When participants were asked to brainstorm possible solutions to the existing problems in caregiver services delivery discussed during the focus group, some common themes to the solutions emerged.

### *Engaging Volunteers*

Engagement of volunteers was discussed as an important solution to many problems, although there were some challenges associated with it. Every participant agreed that volunteers would be beneficial and would address many of their service delivery problems. However, most believed that it would be very difficult to develop a volunteer program within their agency, due to limited staffing resources, lack of time, and limited funding. Training volunteers was identified as necessary to successfully engage volunteers. As one participant stated:

*"It does take a lot of time and training, and someone must be available to supervise and manage the volunteers. So we just haven't really had the capacity to do that. Partly, also because the territory we cover is across different counties, so to be able to have a pool in each county that could go out and visit with caregivers and their*

*families would just be more coordination that we couldn't really do. So usually, when people are looking for volunteers, we usually just try to connect them with services that already provide that, since we are not able to."*

Agencies that already had volunteers described the experience as successful and valuable to caregivers, and stressed the importance of training and supervising the volunteers. Another participant shared,

*"There is training involved, there is no doubt about it, but the investment is strategic. And it doesn't happen overnight. If it weren't for volunteers, we would not be able to deliver the services we are able to deliver because of finances."*

### *Outreach and Education*

Many agencies have been investing their efforts into outreach and education, to reach out to caregivers in their community. This is particularly important to caregivers who are from a different cultural community. One participant working mainly with the Vietnamese population stated that she had seen some positive changes due to their ongoing outreach and education about the benefits that come with the caregiver services and how those benefits can benefit the whole family of their clients.

*"I think as we are gradually moving forward, especially in the Vietnamese community. We have been seeing a lot of time now, [one issue is] with payments of fees and the next generation not quite understanding a lot of the benefits that comes in with all of these services; you know, having mom, dad, or grandma come to a center, and if grandma says "No, I want to stay home." Then that's it and they don't push a little more. I really still think, especially in those cultural populations, there really needs to be a push of education on how all parties in the whole entire family can benefit. That's still a missing link out there in the community."*

Another participant mentioned that continuous outreach to educate caregivers was important to promote their awareness of available services in a community. Others said that outreach and education could link caregivers who were reluctant to utilize available services, because providing education and outreach could empower them and make them feel like it is acceptable to try something new. Another participant emphasized the importance of grassroots and more area-focused education and outreach in communities with low socioeconomic status based on her experience working for church in a vulnerable community, because she found that aging was one of the areas where they did not know how to respond. She suggested that the community could benefit from case management social work that focused on the individual problems of caregivers and/or care-receivers.

### *Collaboration among Agencies*

Two participants commented on the idea of collaborating with other agencies to share a pool of volunteers:

*“I think it would be a good solution, but I don’t know how this would ever work, because someone would have to house it. If it was like a central pool of volunteers, where one could call and someone could come and visit, and if that was something that existed county wide that you can tap into...even if it’s once a week, and can visit for four hours and you don’t have to live in a certain city, and you don’t have to be on hospice, you don’t have to be connected to a certain organization.”*

*“Again, if each agency sets up their own volunteer pool, we have a lot of people investing a lot of time in processes again, so how, in the caregiver realm, do we coordinate those kinds of services? We haven’t used volunteers really for the same reasons.”*

These comments lead into the second solution discussed: coordination and collaboration among service providers. Participants noted that coordinating with other agencies would help fill in the gaps for clients. Another participant explained that duplicating services is not the best use of funding, and that a database, where every agency is connected, would be beneficial. She explained:

*“It’s not the best use of funding, because we are all doing the same thing over and over. I’m talking about assessments, paperwork, etc. We happen to use a database that allows us in some instances...to see what people are involved in already meeting our clients. We may know they are involved in Meals on Wheels or a senior lunch program or other programs within the community, but not everybody is connected. So there are a lot of things that we don’t even know that things exist in the community.”*

One participant described a successful model that occurred in another geographic location, where each agency took on a particular service, instead of all agencies doing the same thing:

*“Three to four agencies got together, it took them a long time, but they figured out how to have one agency do intakes for all of them. They just spread out intake, marketing, outreach, etc. From the standpoint of the caregivers or the person in a community, they don’t really care; they just want to know, how do I get help? It wouldn’t be all agencies, but could there be 2 or 3 initially that really did come together at all levels. The CEOs have to commit and the boards have to commit. Ultimately, they had one brochure, and spelled out, “if you want transportation, you go here, and so on.”*

### ***Putting it All Together***

The currently available family caregiver support services offered by various organizations in Santa Clara County were identified through responses to the online survey. Respondents included both recipients and non-recipients of Title III E funding for caregiver services.

The results show that except for information and assistance, caregiver services in

each NFCSP service category are not consistently provided across agencies which may mean that clients who primarily receive their services from a single agency may have needs for other services that remain unmet. Particularly these unmet needs may be in the areas of caregiver support groups, case management, and respite services which are provided by less than half of the non-Title III funded agencies.

Although Title III E funding has helped some local agencies provide more comprehensive support services to caregivers, it has not mitigated service discrepancies among agencies, which could potentially limit the choices of caregivers. These service gaps can create inconveniences for caregivers, because they are unable to receive the comprehensive caregiver services in the agency they prefer. Thus, they might have to be referred to another agency, which means that they have to start the process from the beginning.

Since Title III E funds are not available to all agencies providing services to caregivers, and in limited amounts to those agencies that do receive funds, they are insufficient to meet the multifaceted needs of family caregivers.

Analysis of the data from the focus group indicates that a lack of funding is one of the most common problems that providers face in addressing caregiver needs. Service providers noted that respite care was the greatest unmet need experienced by caregivers.

Although increased funding can be one of the solutions to alleviate the problems in caregiver support services delivery, it was also perceived to be one of the biggest factors in preventing agencies from working together. Funding requirements were often perceived as being less flexible in terms of how money is spent, resulting in duplication of many services among agencies. This means that caregiver support services offered by various agencies do not necessarily reflect the unique needs of caregivers. As one participant suggested in the focus group, more integrated services delivery, such as collaborative work among agencies and developing a caregiver client database that can be shared among agencies, might be possible solutions to this problem and would be a better use of funding. One example where duplication of services might occur is if a caregiver gets an assessment from one agency but is referred to another because the caregiver requests respite services. The second agency will also do an assessment before offering respite services, thus duplicating the assessment. A shared database where client records could be accessed by the receiving agency was perceived as a possible solution to eliminating such duplication.

A lack of caregiver services available in languages other than English was perceived by focus group participants to be a significant service delivery issue. Participants in the focus group commented that language capability is always a problem. Inability to access the services in the caregiver's native language discourages caregivers from seeking support from agencies and introduces delays in receiving services they need. Interestingly however, the results of the online survey indicated that the provision of culturally and linguistically appropriate services was not ranked among the top five unmet needs of caregivers suggesting that language capability is not one perceived to be one of the major barriers to service delivery as compared to other issues. Thus, further study that provides more specific information regarding unmet need due to lack of language capacity of service

providers is recommended.

As the results from the quantitative data show, many agencies rely on volunteer staff in various service areas to deliver caregiver support services, and the participants in the focus group were strongly aware of the potential benefits offered by volunteers. One agency has been very successful in implementing a volunteer training program and using their well-trained volunteers to deliver their caregiver support services. Although there are some challenges in terms of volunteer training, as some participants mentioned in the focus group, volunteers are usually people who devote their time and energy to helping those in need. Thus, if agencies offer the tools for volunteers to get the appropriate training, their impact on caregiver support services delivery can be substantial.

Taking a collaborative and coordinated approach, rather than a competitive approach, at the local level agencies may help mitigate many of the problems that agencies are currently facing particularly in service gaps, service duplication, outreach, and education. This will ultimately enhance community caregiver support networks.

#### *Some Important Caveats to these Findings*

It is important to understand the following issues related to the survey sample before extrapolating the results.

- 1) Only 41% of the service providers in the sampling frame actually completed the online survey which limits the generalizability of the findings of this study in terms of developing a more complete profile of caregiver services in Santa Clara County.
- 2) Not all agencies receiving Title III E funding for providing caregiver services responded to the survey. Notably missing among the survey participants are the smaller agencies that primarily provide services to Asian caregivers as well as some large agencies known to provide services to larger numbers of Latino caregivers.
- 3) There was only one for-profit agency that took the survey and thus the data do not adequately reflect their unique circumstances in providing services to caregivers.

The lack of responses could be in part due to the length of the survey and the amount of information asked. Participants may have felt overwhelmed and unprepared and/or busy and didn't have time. Some participants opened the survey and agreed to participate, but never did. It is also possible that some agencies did not provide any caregiver services and hence did not respond.

Another limitation was that many agencies do not collect data on the number of caregivers they serve or how many caregivers receive certain types of services; therefore, there was little information in this area. This inability to collect necessary data from agencies can be a challenge to providing an accurate picture of the current caregiver support services and developing or improving caregiver support service plans in the future. In addition, this may ultimately work against service providers, as they are not able to demonstrate a need for their services. These data could provide a clearer picture of the met

and unmet needs of the overall caregiver population.

Finally, the study is also limited by the fact that a very small number of service providers participated in the focus group. One explanation for the lower than expected turnout was the inclement weather on the day the focus group meeting was scheduled. Additional focus groups with different types of service providers will be helpful in obtaining a more complete picture.

*Recommendations for Further Investigation on Caregiver Services and Needs*

Additional research in specific areas can provide a better picture of existing caregiver support services in Santa Clara County and specific recommendations for further data collection are made below:

1) Data on numbers of caregivers served through Title III E funds may be obtainable from the annual reports submitted to the Council on Aging.

2) Additional focus groups could be conducted to capture the experiences of a larger number and variety of service providers. This could include non-traditional service providers such as ethnic and cultural organizations and places of worship that may have very different access to the community as compared to social services organizations.

3) Data on how caregiver needs for information and services are handled by employers (e.g. corporations) can provide additional perspective on resources available and needed in Santa Clara County.

4) Finally, a survey of caregiver support agencies in other geographic areas with similar demographics might provide useful insights into the nature of support needed and offered to address the needs of diverse caregivers.

It is also recommended that future surveys be shorter in length and an alternative to caregiver service hours be used as a measure of service delivery as many agencies did not have this information available.

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## Appendix A

### Caregiver Support Services Online Survey

#### 1. Consent Form *(edited for this report)*

Exploring the Nature of Existing Caregiver Support Services in Santa Clara County  
The purpose of this research project is to gather baseline data on existing services offered to family caregivers in Santa Clara County and to find areas in which the delivery of services to clients can be improved. This is a research project sponsored by the Aging Service Collaborative (ASC) of Santa Clara County led by the ASC Caregiver Support Team and The Health Trust. This research project is being conducted by Kazuko Kuramoto and Jessica Hernandez, MSW students at San Jose State University. Your agency is invited to participate in this research project because you are providing support services to caregivers.

Your participation in this research study is voluntary. You may choose not to participate. If you decide to participate in this research survey, you may withdraw up until the submission of the survey. If you decide not to participate in this study or if you withdraw from participation at any time, you will not be penalized.

The procedure involves completing an online survey that will take approximately 15 minutes. The survey questions are related to your agency's services offered to caregivers, which are typically available to the public. Your responses from the online survey will be shared in a report that will be available to the public.

All data are stored in a password protected electronic format. The results of this study will be used for scholarly and public purposes and will be shared with San Jose State University faculty and the Aging Services Collaborative.

ELECTRONIC CONSENT: Please select your choice below. Clicking on the "agree" button below indicates that:

- you have read the above information
- you voluntarily agree to participate
- you are at least 18 years of age

1. If you do not wish to participate in the research study, please decline participation by clicking on the "decline" button.

Agree to participate

Decline to participate

#### 2. Caregiver Support Survey: Agency Information

Please complete the following questions about your agency.

1. What is the name of your agency?

2. Please provide your name, agency position, and contact information.

3. What description best represents your agency? Check all that apply.

- Adult Day Center
- Hospice
- Care Management
- Hospital/Medical Group
- Senior Center/Community Center
- Home Care
- Other (please specify)

4. Which of the following describes your agency? Check only one.

- For-profit
- Non-profit
- Faith-based community organization

5. Does your agency receive funding from Older Americans Act/NFCSP (National Family Caregiver Support Program)/Title III E Grant?

- Yes
- No

6. What is your agency's service area within Santa Clara County? Check all that apply. If your agency serves caregivers in all of the cities in Santa Clara County, check "Entire Santa Clara County."

- Entire Santa Clara County
- San Jose
- Campbell
- Cupertino
- Gilroy
- Los Altos
- Los Altos Hills
- Los Gatos
- Milpitas
- Monte Sereno
- Morgan Hill
- Mountain View
- Palo Alto
- Santa Clara

- Saratoga
- Sunnyvale

7. What are the main referral sources within Santa Clara County to your agency? How are caregivers sent to you? Check all that apply.

- Word of mouth
- Other community based organizations
- Medical providers
- City agencies
- County agencies
- Brochure
- Email
- Newsletter
- Other (please specify)

8. Does your agency have a website that offers/provides caregiver resources?

- Yes
- No

9. What languages, other than English, do you provide caregiver services in? Check all that apply.

- Spanish
- Cantonese
- Mandarin
- Korean
- Japanese
- Vietnamese
- Tagalong
- Other (please specify)

10. What languages are you NOT able to provide caregiver services in?

- Spanish
- Cantonese
- Mandarin
- Korean
- Japanese
- Vietnamese
- Tagalong

Other (please specify)

**3. Caregiver Support Survey: Agency Services**

Please complete the following questions by entering your agency's FY 2009-2010 caregiver services data.

1. Does your agency currently use volunteers to serve caregivers?

- Yes
- No

If yes, in what capacity? (i.e., transportation, information & assistance, etc.)

2. Does your agency provide information and assistance related to older adults and caregiving?

(Information and assistance provides older adults and caregivers with information on services available in the community -i.e., resources, placement information, and referrals, etc.). If no, skip to page 4.

- Yes
- No

3. If yes to Question 2, how many unduplicated older adults and caregivers did you provide information and assistance to in Fiscal Year (FY) 2009-2010?

- Data not collected

# of unduplicated older adults and caregivers (estimation acceptable)

**4. Caregiver Services Provided**

In FY 2009-2010, which of the following services did your agency provide to caregivers?

DO NOT INCLUDE RESPITE SERVICES HERE

Check all that apply and enter the appropriate data.

1. Caregiver Assessments:

*A support service that explores options and courses of action for caregivers by identifying physical health, psychological and social support, and training needs, etc.*

- Yes, this service was provided to caregivers in FY 2009-2010
- No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

2. Caregiver Counseling (individual or group):

*A support service which may provide guidance on the responsibilities of the caregiving*

*role, therapy for stress, depression, and loss; includes direct sessions and telephone consultations.*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

**3. Caregiver Support Group:**

*A supportive service provided to a group of 3-12 caregivers that is led by a competent facilitator, conducted at least monthly, for the purpose of sharing experiences and ideas to ease the stress of caregiving and enhancing decision making and problem solving related to the caregiver's role.*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

**4. Caregiver Training/Education:**

*Workshops or one-on-one individually tailored sessions, conducted either in person or electronically by a skilled trainer to assist caregivers in developing skills and the knowledge necessary to meet and enhance their caregiving roles.*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

**5. Caregiver Case Management:**

*The coordinating and monitoring the provision of formal caregiver-related services in circumstances where caregivers are experiencing diminished capacities due to mental impairment or temporary severe stress and/or depression.*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

**6. Did your agency offer any other caregiver services in FY 2009-2010?**

**5. Caregiver Support Survey: Respite Services**

Please complete the following questions by entering your agency's FY2009-2010 respite services data.

1. Does your agency provide respite?

If no, skip to page 7 related to additional agency services.

- Yes
- No

2. In FY 2009-2010, what was the total number of unduplicated clients who received respite?

(Unduplicated is counting a person once regardless of how many times interaction occurred)

- Data not collected
- # of unduplicated clients (estimation acceptable)

**6. Respite Services Provided**

In FY 2009-2010, which of the following respite services did your agency provide to caregivers?

(Respite care enables caregivers to be temporarily relieved from caregiving responsibilities)

Check all that apply and enter the appropriate data.

1. Respite In-Home Supervision:

*Temporary care that includes supervision and friendly visiting by an appropriately skilled provider or volunteer in order to prevent wandering and health or safety incidents.*

- Yes, this service was provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

2. Respite Homemaker Assistance and Personal Care Assistance:

*Includes household chores (ex: meal prep, light housework, medication management) and is performed for someone unable to perform these tasks on their own and assistance with ADLs.*

- Yes, this service was provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

3. Respite Adult Day Care:

*The temporary respite care where the care receiver attends a supervised/protective, congregate setting during some portion of a day, and includes access to social and recreational activities.*

- Yes, this service was provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

4. Respite Out-of-Home Overnight:

*Offers temporary care for varying lengths of time. Group homes, hospitals, nursing homes, and other specialized facilities provide emergency and planned overnight services, allowing caretakers 24-hour relief.*

Yes, this service was provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

**7. Caregiver Support Survey: Additional Agency Services**

In FY 2009-2010, which of the following additional services did your agency provide to caregivers?

Check all that apply and enter the appropriate data.

1. Assistive Devices:

*Examples include -wheel chairs, walkers, chair lifts, electronic pill dispensers, over bed tables, commodes, shower chairs, car transfer aid*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

2. Home Adaptation Assistance:

*Examples include -grab bars, entrance ramps wall switch extension handles*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

3. Caregiver Financial Assistance

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010

If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

4. Caregiver Legal Assistance:

*Examples include -legal advice, counseling, or administrative and judicial representation by an attorney that is provided to a caregiver with legal needs associated with his/her caregiving responsibilities*

Yes, this service was provided to caregivers in FY 2009-2010

No, this service was NOT provided to caregivers in FY 2009-2010  
 If yes, enter: 1. the # of hours and 2. the total # of unduplicated caregivers served

5. Placement Services:

*Examples include -placement into LTC, B&C, Assisted Living, CCRC, etc.*

Yes, this service was provided to clients in FY 2009-2010  
 No, this service was NOT provided to clients in FY 2009-2010  
 If yes, enter: 1. the # of hours and 2. the total # of unduplicated clients served

6. Meal Prep Assistance

Yes, this service was provided to clients in FY 2009-2010  
 No, this service was NOT provided to clients in FY 2009-2010  
 If yes, enter: 1. the # of hours and 2. the total # of unduplicated clients served

7. Transportation Assistance

Yes, this service was provided to clients in FY 2009-2010  
 No, this service was NOT provided to clients in FY 2009-2010  
 If yes, enter: 1. the # of hours and 2. the total # of unduplicated clients served

8. Did your agency offer any other additional services in FY 2009-2010?

**8. Caregiver Support Survey: Total Caregivers Served**

Please complete the following questions by entering the FY 2009-2010 data.

1. How many unduplicated caregivers did you provide ALL caregiver services to from all funding sources in FY 2009-2010?

(Unduplicated is counting a person once regardless of how many times interaction occurred)

Data not collected  
 Unduplicated # of caregivers (estimation acceptable)

2. List the racial/ethnic demographics (percentage) of ALL caregiver clients served in FY 2009-2010.

- White
- Black or African American

- Asian
- Hispanic/Latino
- American Indian/Alaska
- Native
- Native Hawaiian or Pacific
- Islander
- Other
- Unknown

**9. Caregiver Support Survey: Agency Needs**

Please complete the following questions to identify the resources or services that are needed by your agency.

1. What are the most common needs or requests identified by caregivers you serve?

PLEASE SELECT TOP 3.

- In home care
- Respite care
- Housing
- Legal
- Financial/Benefits assistance
- Out of home placement
- Training/Education
- Emotional Support
- Other (please specify)

2. On a scale of 1-10, rank the following needs of caregivers you serve with (1) being the greatest unmet need of caregivers. Use the list provided.

- Respite care
- Affordable/low cost case management
- Transportation
- Meal services
- Culturally and linguistically appropriate services
- Caregiver group training
- Caregiver support group
- Caregiver individual coaching
- Financial assistance
- Legal consultation
- Care in rural area

- Counseling/support
- Other (please specify)

3. What are the primary reasons caregivers are ineligible for services at your agency?  
Check all that apply.

- Income requirements
- Ability to pay
- Diagnosis of care recipient
- Level of impairment of care recipient
- Language capability
- Geographic location
- Other (please specify)

4. Have you had to reduce services or resources for caregivers in the past year?

- Yes
- No

5. If Yes to question #4,  
Why?

Which programs or services were eliminated?

6. Identify what barriers exist that prevent caregivers from receiving the support they need. Check all that apply.

- Cultural
- Financial reasons
- Reason is not known
- Other (please specify)

7. How likely would you or your agency use a well-trained volunteer to assist in the delivery of caregiver services?

- Very likely
- Somewhat likely
- Not likely

8. How likely would you or your agency use a well-formed volunteer caregiving training

curriculum if available?

- Very likely
- Somewhat likely
- Not likely

9. Do you have anything else to share with us about caregiver services in the community?

10. Would you be interested in participating in a focus group related to this subject in the next few weeks?

- Yes
- No
- Maybe

## Appendix B

### Focus Group Questions

1. Problems of service delivery

1) Can you describe the problems you have had in service delivery across the span of caregiving?

2) Can you offer a case example and describe what went well and what did not go well? Or one of each?

2. Possible Solutions

1) How might volunteers be used in some of these problems you've described?  
(15 min)

1) How might other agencies be used or how might we work with other agencies differently to address these problems you've described? (15 min)

## **Appendix C**

### **Agencies participating in the survey**

1. All Care Plus, Inc
2. Alzheimer's Association
3. Avenidas senior center
4. Bill Wilson Center, Centre For Living With Dying Program
5. Catholic Charities of Santa Clara County
6. Community Services Agency of Mountain View and Los Altos
7. Council on Aging, Silicon Valley
8. Family Caregiver Alliance
9. Heart of the Valley, SERVICES FOR SENIORS, Inc.
10. Hospice of the Valley
11. Respite and Research for Alzheimer's Disease
12. SarahCare of Campbell
13. Seniors At Home, a division of Jewish Family and Children's Services
14. Sunnyvale Senior Center
15. Yu-Ai Kai/Japanese American Senior Services