

part

2



Family  
Caregiving

## REVIEW OF FAMILY CAREGIVER SUPPORT NEEDS IN ORANGE COUNTY

The importance of family caregivers to the economy and the health and well being of frail elderly persons requires that the Orange County Office on Aging, the Orange County community of service providers, and the Orange County community at large know and understand them.

This report examines older adults as caregivers and care recipients, addressing the issues of who the caregivers are, what the value of their services is, what they give up to meet the needs of those they care for, and what the cost is to community businesses in lost hours and talent.

In FY 2001-02, public forums were facilitated by the Community Services Agency/Office on Aging (CSA/OoA) focusing specifically on identifying the needs of, and resources available to, families and caregivers of older adults. The information gathered regarding needs, resources, and gaps in services was used by OoA to develop a preliminary Plan for Caregiver Support Services.

In addition, the results of the Multilingual Telephone Survey of Older Adults, conducted in the first quarter of FY 2001-02 by research staff of California State University at Fullerton and Chapman University with collaboration of a consortium of service providers, were released in January of 2002.

Lastly, in early 2002 the County of Orange Health Care Agency, in collaboration with the Office on Aging and County Human Resources, conducted a survey of county employees regarding caregiving. The results of the survey provided useful new data regarding caregiving among county employees and allowed for the development of educational programs for county employees. (See Appendix A for findings.)

## WHO IS IN NEED OF CARE?

Before considering the needs of family and other informal caregivers, it is important to assess the population in need of care.

The 2002 Orange County Health Needs Assessment (OCHNA) survey findings indicated that 9.3% of households headed by a person age 65 or older currently receive help with daily care. This percentage varied considerably by ethnicity.

### Care Receivers by Ethnicity

Ethnic Affiliation	% Receiving Help with Daily Care
Latino Hispanic	13%
White	8%
African American	Less than 1%
Vietnamese	25%
Other Asian/Pacific Islander	Less than 1%

Source: OCHNA, Spring 2002

Out of 1,035 randomly selected older adults in the Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001 (hereafter referred to as the Multilingual Survey), 43.6% stated that they have difficulty with one or more daily life activities. 14.6% had help from someone else.

The OCHNA report provides information about the ethnic/racial distribution of individuals receiving help with daily care. The Multilingual Survey showed differences in primary language (rather than ethnicity alone) to be more indicative of differences among ethnic groups in percentages of those receiving care. In addition, the variance in methodologies chosen by the researchers does not allow for exact comparison of data between the two surveys.

**Care Receivers by Language**

Primary Language	% Receiving Help with Daily Care
English	28%
Spanish	43%
Vietnamese	59%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

**Care Receiver Assistance**

Type of Care Provider	% Receiving
Hired Help	37%
Spouse	26%
Other	17%
Child or Grandchild	15%
Other Relative	5%

Source: OCHNA, Spring 2002

Of the 9.3% in the OCHNA survey who receive help with daily care, 63% receive help from "informal" sources such as family, friends, and neighbors. Approximately 37% hire someone to provide assistance.

In order to serve as a planning resource, the Orange County Long Term Care Multilingual Senior Needs Assessment report on the type of care provider includes the percentage of older adults with difficulty in performing daily activities who receive help from no one. Also, according to the report, the primary language in a household makes a difference in the type of help that is used.

**Care Receivers: Level of Care**

Type of Care Provider	% Receiving Care				
	English	Spanish	Vietnamese	Other	Total
Spouse	26%	22.1%	9.7%	37.1%	21.1%
Other Relative	31.2%	71.8%	82.6%	44.4%	51.6%
Friend	6.1%	1.4%	1.9%	11.1%	4.4%
Agency Volunteer	4.6%	0.7%	0.3%	0.0%	2.7%
Paid Worker	32.1%	4.0%	5.5%	7.4%	20.1%

**Percent Needing Care Who Are Without Assistance**

	English	Spanish	Vietnamese	Other	Total
No Assistance	41.6%	41.3%	20.1%	48.1%	36.9%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

The tables above indicate that a significant number of individuals with specific needs to maintain their daily lives are without any assistance. It also shows that Vietnamese older adults are more likely than any other language group to be assisted by their families for all needs. Older Vietnamese also appear less likely to be caregivers for a spouse than other language groups. In both Spanish speakers and Vietnamese speakers paid workers and agency volunteers are rarely used in comparison with English speakers, who employ paid workers at eight times the rate of Spanish speakers and almost six times the rate of Vietnamese speakers.

## WHO ARE FAMILY CAREGIVERS?

Families, not social service agencies, nursing homes or government programs, are the mainstay underpinning long term care (LTC) for older persons in the United States.

According to the most recent National Long Term Care Survey, more than seven million persons are informal caregivers – providing unpaid help to older persons who live in the community and have at least one limitation on their activities of daily living. These caregivers include spouses, adult children, and other relatives and friends.

The difference between family caregivers and paid caregivers is not always a distinct one. In Orange County, for example, about 75% of the caregivers paid for by the In- Home Supportive Services (IHSS) program are related to the care recipients. Often, the modest wage paid by IHSS is what allows the family member to remain at home with the older adult and they frequently provide services far beyond what they are paid for.

In some cases, the isolation and frustration of caring for a dependent older adult has the unwanted outcome of elder abuse. Usually, these families have multiple problems. Formal resources that increase socialization and access to aid for multiple issues afford the opportunity for the affected caregivers to mitigate unhappy, sometimes tragic, situations within caregiver households. It should also be stated that although abuse by overburdened caregivers is a serious issue, the greater risk is that the stress of caregiving may lead to chronic health problems and early death for the caregiver.

Predating the national recognition of "informal" family caregivers, California was the first state to use public dollars for a statewide system of services for family caregivers. California Caregiver Resource Centers were developed as a result of the Comprehensive Act for Families and Caregivers of Brain Impaired Adults, as amended in 1984. Although available to caregivers of adults 18 and older, the majority of the care recipients (88% in 2001) are 55 and older. The Caregiver Resource Centers and the statewide system were among the Model Programs for the National Family Caregiver Support Program described below.

At the national level, recognizing the important role of "informal," family caregivers, Congress enacted the Older Americans Act Amendments of 2000 (Public Law 106-501) establishing an important new program, the National Family Caregiver Support Program (NFCSP). This program marks a change in focus from the needs of the care recipient to those of the caregiver. The program allocates funding to pay for the federal share of the cost of carrying out programs administered throughout the nation by local area agencies on aging, or entities that such area agencies on aging contract with, to provide multifaceted systems of support services for family caregivers, grandparents and older individuals who are relative caregivers.

### National Family Caregiver Support Program (NFCSP) Definitions

- (1) FAMILY CAREGIVER means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual (60 or older).
- (2) GRANDPARENT OR OLDER INDIVIDUAL WHO IS A RELATIVE CAREGIVER means an individual, age 60 or older, who is a grandparent or step-grandparent of a child (an individual 18 years old or less), or a relative of a child by blood or marriage, and
  - (A) lives with the child;
  - (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and
  - (C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally.

The following are services that can be provided under the NFCSP:

- (1) Information about available services;
- (2) Assistance in gaining access to the services;
- (3) Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles;
- (4) Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- (5) Supplemental services, on a limited basis, to complement the care provided by caregivers.

Consistent with the policy objectives of the Older Americans Act, service providers are required to target these services to older individuals with greatest social and economic need (with particular attention to low-income older individuals) and older individuals providing care and support to persons with mental retardation and related developmental disabilities (as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001)).

A national survey completed in 1997 by the National Alliance for Caregiving and AARP found that just over 23% of all U.S. households with a telephone contain at least one caregiver. Three-fourths (76%) of those caregivers are currently caring for a relative or friend who is at least 50 years old. The remaining 24% report having provided informal care to a relative or friend within the past 12 months, but are not currently doing so.

According to Census 2000 data (Summary File 1), there are 935,287 households in Orange County. Conservatively assuming that 20% contain at least one caregiver, caregiving is being provided in approximately 187,000 households in Orange County, with 140,000 of those involving care for an older adult family member or friend. This estimate seems reasonable given that there are an estimated 40,000+ older adults with Alzheimer's disease in Orange County (according to Alzheimer's Association reports) and that a substantial number of the 35,000 persons aged 85 and older are in need of assistance with one or more activities of daily living.

As the number of older adults who are living longer continues to grow, the need to address the challenges associated with caregiving becomes even more important. The number of older adults receiving long-term care assistance is expected to increase by 24% over the next two decades and much of it will be provided at home by family members.

In addition to providing care to other older adults, many seniors provide primary care to their grandchildren under the age of 18 or to other related or non-related children. Some older adults have responsibility of caregiving both for children and at least one older adult. The financial, physical, and emotional toll of caregiving on this group of caregiver older adults has become a national interest only recently.

Because the data collection systems do not always use the same units of measure or the same age ranges, it is not always possible to make direct comparisons between national, state and county statistical information. However, trends and important comparisons will be noted.

## FAMILY CAREGIVING

According to the Family Caregiver Alliance (FCA) there is wide latitude in the estimates of the number of caregivers in the U.S., depending on the definitions and criteria used. The FCA estimates are based on homes with telephones. All of the surveys included in this document, other than the Orange County Employee Caregiving Survey, are telephone surveys.

In order to assess caregiver needs and make projections with regard to caregiving over the next 20 years both nationally and here in Orange County, it is important to appreciate certain general characteristics of caregivers and certain macro trends with regard to caregiving nationally.

### General Demographic Trends

- Nationwide, nearly one out of every four households (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over. A recent statewide telephone interview study by the Center for the Advanced Study of Aging Services at UC Berkeley estimates that 16% of all California households (1.8 million) with telephones are caregiver households.
- According to a Spring 2002 report from the Orange County Health Needs Assessment (OCHNA), of those respondents ages 18 to 64, 12.6% (approximately one eighth of the age segment) indicated that they are responsible for the care of an older adult. We do not have an estimate of the percentage of caregiver households in Orange County. In this survey caregivers had to self-identify; for many ethnic groups in Orange County there is no unique caregiver role.
- By the year 2007, the number of caregiving households in the U.S. for persons age 50 and over could increase from 22.4 million to 39 million.
- Nationally, 5.8 - 7 million people (family, friends and neighbors) provide care to persons 65 and older who need assistance with everyday activities. 5 million informal caregivers provide care for someone aged 50 and over with dementia.

### General Gender Trends

Nationwide, approximately 75% of those providing care to older family members and friends are female. California mirrors the national statistics; 75% of the caregivers are women.

- Men who are caregivers spend 50% less time providing care than female caregivers.
- The person most likely to be providing care to an older person is a daughter, whether at the national, state, or county level.

### General Familial Trends

Other studies have found that a much higher percentage (15%- 24%) of caregivers were caring for a friend or neighbor as opposed to a family member. In California friends care for 12% of the care recipients. In the Orange County analysis that included the category "friends," the percentage varied greatly with primary language spoken at home.

Nationwide, among adults aged 20-75 providing informal care to a family member or friend of any age, 38% provide care to aging parents and 11% provide care to their spouse. In California, 49% provide aid to a parent and 12% to a spouse or significant other. Of the two Orange County surveys, the Multilingual Survey most closely reflects the direction of the national and state data. In that survey 13% provide care to a spouse and 33% are other relatives who provide care. The OCHNA survey differs significantly in direction and number, reporting 26% caring for a spouse and 15% caring for a parent or grandparent.

- In a national sample of caregivers who live with their care recipients, spouses account for about 62% of primary caregivers while adult children comprise 26%.
- Secondary caregivers are more likely to be adult children (46%) than spouses (16%).
- Of those caring for someone aged 50 and over, the average age of family caregivers is estimated at 46 years.

Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html)), A PROFILE OF FAMILY CAREGIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS <http://cssr.berkeley.edu/aging>.

### CAREGIVING AND ETHNICITY

California is the most ethnically diverse state in the United States.

In order to understand how to target those caregivers most in need of services, the impacts of culture and ethnicity on those who need and provide supportive services, particularly supportive services as critical and highly personal as caregiving services, must be understood.

To understand the extent to which difference in ethnicity, social classes, and language impact caregiving, the population must be surveyed to collect this information. National statistics do not separate these three categories, presenting ethnic/racial differences without the useful categories of primary language and social class (as defined by income, educational level, and occupation).

Orange County researchers have removed some of the data retrieval barriers for planning. The Multilingual Survey found that ethnicity was not the primary determinant of significant differences in Orange County subpopulations. The more salient category to determine differences in response was primary language within the households. Information on Orange County caregivers and care recipients is reported both in terms of ethnicity (OCHNA ) and of primary language (Multilingual Survey).

- Family caregiving differs across ethnicities and cultures. For example, a study of Americans between the ages of 45 and 55 - the "baby boomers" - found that a much higher percentage of Asian Americans provide care for older relatives than do White, non-Hispanic Americans:

**Percent of Individuals Aged 45 - 55 Caring for Parents, by Ethnicity**

% Providing Care	Ethnicity
42%	Asian Americans
34%	Hispanic Americans
28%	African Americans
19%	White

Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html)), A PROFILE OF FAMILY CAREGIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS <http://cssr.berkeley.edu/aging>

- National data indicates that about 43% of baby boomers born outside of the U.S. - compared to 20% of boomers born in the U.S. - provide care for older relatives.
- Ethnic differences are also found with regard to the care recipient. Among people aged 70 and over and who require care, Whites are the most likely to receive help from their spouses; Hispanics are the most likely to receive help from their adult children; and African Americans are the most likely to receive help from a non-family member.

Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html)), A PROFILE OF FAMILY CAREGIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS <http://cssr.berkeley.edu/aging>

## EMPLOYMENT AND CAREGIVING

Caregiving takes a toll not only on the health of the caregiver but also on the caregiver's ability to participate in his or her work life.

Therefore, targeted services will benefit not only the caregiver but the business community as well.

- 25% of all workers provide care for someone 65 and over.
- Just over half of all caregivers for persons aged 50 and over are employed full-time and almost two-thirds are employed either full- or part-time.
- Among Californians, about 35% of caregivers reported being employed full time, 14% were employed part-time, 23% were retired, 4% were on leave of absence, and the remaining 24% were not employed.

*Source: Scharlach, Andrew, et al., "A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers," January 31, 2003*

- Among working caregivers of a family member or friend aged 65 and older, two-thirds report having to rearrange their work schedule, decrease their hours, or take an unpaid leave in order to meet their caregiving responsibilities. In California, among working caregivers, approximately 77% indicate that there have been no changes in their job status because of caregiving. Another 13% report reducing the number of work hours and about 4% changed jobs. However, 21% reported having missed work in the two weeks before being interviewed – 15% were absent for at least one entire day (of those having missed work, 4% were absent for 3 or more days), and 18% took some time off during the workday. On average, people who missed work in the two weeks prior to being interviewed missed 20.7 hours each.

*Source: Scharlach, Andrew, et al., "A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers," January 31, 2003*

- Among surveyed employees of the County of Orange, 16% have reduced work hours due to caregiving. The median number of hours lost in the month prior to the survey was less than one hour, although 10% of the employees reported over 10 hours of work lost due to caregiving responsibilities. Approximately 16% had taken extended personal leave due to caregiving. As many as 74% had taken some vacation or sick time for caregiving responsibilities (11.5% take over 40 hours of sick or vacation time annually for caregiving).

*Source: County of Orange Employee Caregiver Survey 2002.*

- Among County of Orange workers, 19% believed their caregiving interfered with their work performance, productivity, or advancement at work "somewhat, very much, or completely."

*Source: County of Orange Employee Caregiver Survey 2002.*

- Caregivers of people aged 50 and older spend an average of 17.9 hours per week providing care. This figure increases to 20 hours per week among those providing care for individuals aged 65 and over. In California, caregivers who assist someone with severe memory problems spend an average of 53.7 hours per week providing care, as opposed to an average 34.1 hours for care recipients without severe memory problems.
- 20% (4.5 million out of 22.4 million) of those caring for family or friends aged 50 and older spend over 40 hours per week providing care, with some providing constant care.
- Ethnic differences exist in the average number of hours of care provided per week to individuals aged 50 and over: African Americans 20.6 hours; Hispanics 19.8 hours; Whites 17.5 hours; and Asians 15.1 hours.

- The duration of caregiving can last from less than a year to over 40 years. The majority of caregivers provide unpaid assistance for one to 4 years; 20% provide care for 5 years or longer.
- Caregivers spend an average of 4.5 years providing care.

Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html)), A PROFILE OF FAMILY CARE GIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS <http://cssr.berkeley.edu/aging>

- More than 7 of 10 people with Alzheimer’s disease live at home, with 85% of home care provided by family and friends.

Source: Alzheimer’s Association of Orange County

### COUNTY OF ORANGE EMPLOYEE CAREGIVING NEEDS SURVEY

In 2002, County of Orange Employee Caregiving Needs Surveys were distributed with paychecks to approximately 20,250 County employees. Over four thousand surveys were returned, a response rate of 21%.

Because the sample was not truly random but self-selected, there is a risk that mostly individuals with an interest in the topic or a need for services would respond. Even with the non-random sample, however, the response rate was higher than random sample response rates would have been, suggesting that caregiving is an area of considerable concern among county employees.

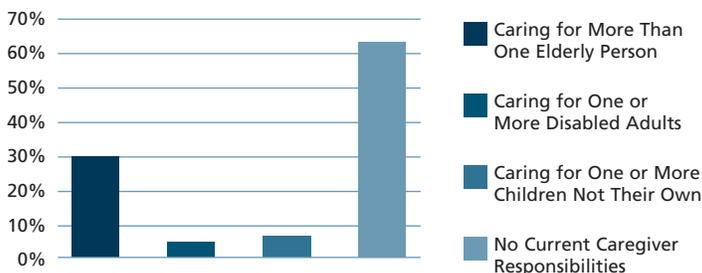
The findings of the Caregiving Needs Survey are given below to show how caregiving in a major Orange County workplace affects the employee and, ultimately, the employer.

#### A. Survey Findings

##### 1) Overall sample

- 30% of respondents provide care to one or more elderly person(s)
  - 20% to one elderly person
  - 8% to two elderly people
  - 2% to three or more elderly people
- 5% provide care to one or more disabled adults
- 8% provide care to children (not their own)
- Over 42% expect to provide care in the next 5 years

**Caregiving Responsibilities of Responding County of Orange Employees\***



\* Because of multiple caregiving roles, as explained on the next page, the total does not add up to 100%.

Of those caring for one or more elderly persons:

- The mean age is 46.4 years
- 74% are women
- 65% are married, 18% single, 14% divorced
- Median annual income: \$40,001 to \$60,000 per year
- Race/ethnicity: 57% White, 22.5% Latino/a, 7% Vietnamese, 3% African American/Black, 3% Chinese, and 3% Asian/Pacific Islander.

### **Grandparents/Multiple Caregiving Roles**

1) Of those who provide care for a child who is not their own, 43% provide care for a grandchild. These grandparents are part of a growing number of Americans who for a variety of reasons are raising their grandchildren. These grandparents need a new set of resources in order to be able to work and raise grandchildren in a world much different from the one in which they raised their own children.

2) Of those who provide care for at least one elderly person, 9% also provide care for a disabled adult and 12% provide care for a child(ren) not their own, i.e. grandchild, niece/nephew. Caregivers with these multiple generational roles are deemed the "sandwich generation." They are sandwiched between caregiving responsibilities for a generation before and after themselves. Some of the individuals who find themselves in this situation feel squeezed between their competing responsibilities.

Care providers of one or more elderly person(s)

1) Average number of hours of care provided per week:

- Median: 5-9 hours per week;
- 13 % provide more than 20 hours of care per week

2) Characteristics of the primary recipient of care:

- Gender: 72% women, 29% men
- Mean Age: 77.9 years
- Place of residence: 70% live in Orange County
- Almost one-third (31%) live with the care provider:
- Relationship to caregiver: 65% mother, 30% father, 16% mother-in-law, 7.5% father-in-law
- Primary condition/illness: 50% long-term illness, 13% dementia or Alzheimer's

3) Type of assistance provided:

- 68% shopping
- 70% transportation
- 67% socialization
- 21% basic needs

4) Duration of care:

- Median: 3-5 years;
- 9% had been providing care for over 10 years

5) Almost 46% are primary caregivers

6) Caregivers seeking assistance:

- 50% have sought assistance with caregiving duties
- 82% of those sought help from family or friends
- 14.5% sought help from Office on Aging

## 7) Work impacts:

- 16% have reduced work hours due to caregiving.
- Median number of hours lost in past month due to caregiving: less than one hour (10% had lost over ten hours of work in the past month due to caregiving responsibilities).
- 16% have taken extended personal leave due to caregiving.
- Amount of sick or vacation time taken due to caregiving: 74% had taken some time; 11.5% take over 40 hours of sick or vacation time annually for caregiving.
- Degree of perceived interference with work performance: 19% believed their caregiving interfered with their work performance, productivity, or advancement at work "somewhat, very much, or completely."
- 34% would use an elder care program at their workplace, if available. This is an important indicator of the level of disability of the older care recipients. It shows that over a third of the care recipients need a high level of personal care.

## 8) Type of services caregivers would like to receive:

- 17% desire counseling/therapy
- 21% would like support groups at work
- 22% would like to take part in a mentoring program

## 9) Financial impact: Type of expenses caregivers are paying:

- 34% medications
- 17% doctor visits
- 15% home modifications
- 13% in-home care
- 9% day care

It is important to note the basic needs that were expressed by these respondents. Given the cross ethnic/language nature of the county employees, their responses can be used as a benchmark for other employers who are interested in conducting a similar survey or offering caregiving resources to their employees.

## IMPACT OF CAREGIVING ON PHYSICAL HEALTH

*Source: National Alliance of Caregivers Fact Sheet*

- Researchers Richard Schulz and Scott Beach, in a ground breaking study of elderly spousal caregivers (aged 66-96), found that caregivers who experience mental or emotional strain have a 63% higher risk of dying than non-caregivers.
- 31% of those caring for persons aged 65 and older describe their own physical health as "fair to poor." In the California study cited by the National Alliance of Caregivers, 26% of those caring for persons 50 years and older described their health as "fair to poor." The rates were higher for individuals caring for a person with emotional, mental, or memory problems (44% vs 36%). Among caregivers who are clients of the California Caregiver Resource Center System, 66% report significant health problems. According to the Orange County Health Needs Assessment, 51.8% of Orange County adult caregivers of older adults indicate that providing care has been an emotional or financial burden for themselves or their spouse.

The statistics cited above highlight the need to target services to protect and promote the health of caregivers.

*Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html)), A PROFILE OF FAMILY CAREGIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS <http://cssr.berkeley.edu/aging>*

## MENTAL AND EMOTIONAL EFFECTS OF CAREGIVING

Caregiving can be an emotional roller coaster. Caring for loved ones demonstrates love and commitment; however, exhaustion, inadequate resources, and continuous caring can lead to burn out, stress, and depression.

Older persons who lose a spouse respond differently based on whether or not they had been a caregiver for their spouse. Those who had provided care and suffered from stress as a result of their caregiving actually showed improved health behaviors and no increase in distress as a result of their spouse's death. Those who had not acted as a caregiver responded to their spouse's death with an increase in depression and weight loss.

A number of studies have found that female caregivers are more likely than males to suffer from anxiety, depression, and other symptoms associated with emotional stress.

Stress in family caregivers is inversely correlated to income: the less income a caregiver has, the more stress he or she is likely to experience. This relationship is corroborated in the California Profile of Caregivers and information from the Caregiver Resource Center System report.

- Among those in the California Profile of Family Caregivers study, 20% of the respondents indicated that they were highly stressed, either financially, physically, or emotionally, due to caregiving. Of this group, 42% stated that their health was "fair to poor." They also reported that caregiving has created more family conflict (28% vs. 7%) and has been "very much" a hardship for their family (39% vs 7%). On the positive side, the highly stressed respondents agreed more than other respondents that they were contributing to their family and setting an example for the children in the family.
- Studies show that among caregivers, an estimated 46%-59% are clinically depressed. Approximately 49% of female caregivers and 31% of male caregivers experience depression as a result of caregiving. Among spouse caregivers, 21-25% of husbands and 50-52% of wives are depressed.
- Although California's Caregiver Resource Center System aids caregivers of care recipients with brain impairment only and, although care recipients may be any age over 18 years, 88% of the care recipients in their client base in 2001 were 60 years and older. At the statewide level, 57% of the surveyed caregivers report that they are clinically depressed.
- Caregivers use prescription drugs for depression, anxiety, and insomnia two to three times as often as the rest of the population.

These statistics highlight the need to target services to protect and promote the mental health of caregivers.

*Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html)), A PROFILE OF FAMILY CAREGIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS <http://cssr.berkeley.edu/aging>*

## VALUE AND COSTS OF INFORMAL CAREGIVING

Nationally, if the services provided by informal caregivers (i.e. family, friends, neighbors) had to be replaced with paid services, it would cost an estimated \$196 billion annually.

- In 1997, \$83 billion were spent on nursing home care compared to \$32 billion for in-home care. As can be seen by the estimate above, the value of informal caregiving exceeds expenses for nursing home care and home care combined by \$81 billion.
- The cost of informal caregiving in terms of lost productivity to U.S. businesses is \$11.4 billion annually.

*Source: National Alliance of Caregivers Fact Sheet ([www.caregiver.org/factsheets/selected\\_caregiver\\_statistics.html](http://www.caregiver.org/factsheets/selected_caregiver_statistics.html))*

### CUSTODIAL GRANDPARENTING

Caregivers as well as care recipients are often older adults. Orange County family caregivers have responsibility for other family members, also. Older adults are increasingly becoming de facto and de jure parents for their grandchildren. Because of the increasing lifespans of all Americans, older adults are often the caregivers for two or more generations of relatives.

Of adults age 65 and older interviewed in 2001, 18% indicate they are currently providing care for a spouse, parent, child, grandchild, or other relative.

From an analysis of California grandparents raising grandchildren by Minkler and Chehimi, according to the 2000 Census, 1.6% of all California grandparents (294,969 persons) are custodial grandparents. California has the largest number of custodial grandparents among all the states. Another 3.4% (633,321 persons) live in households with grandchildren under the age of 18. An unmeasured number of these individuals are likely to be de facto caregivers.

The Census reported all Orange County grandparents, not just those over the age of 65. In 2000 there were 1,567,077 grandparents in Orange County; over 71,000 Orange County grandparents are living with their own minor grandchildren; 18,792 or over one in four (26.5%) bear responsibility for their minor grandchildren. Almost one in ten (9.4%) have been responsible for their grandchildren for five years or more.

#### Caregiver Care Recipients

Providing Care for	%
Spouse	49%
Parent	18%
Other	14%
Grandchild	12%
Child	7%

Source: OCHNA, Spring 2002

#### Grandparents Living with/Responsible for Their Grandchildren

	Number	Percent of Total
Grandparents living with own grandchildren under 18 years	71,119	100%
Grandparents responsible for own grandchildren under 18 years	18,792	26.5%
Grandparents responsible for own grandchildren under 18 years for five years or more	6,676	9.4%

Source: Census 2000, Summary File 3, PCT8

Not all grandparents who care for grandchildren or other children who are not their own are retired or otherwise unemployed; in fact, 71% of Orange County grandparents who are responsible for their grandchildren are workers. Of the 4,290 Orange County employees who responded to the Survey of Caregiving Needs Among County of Orange Employees (2002), whether or not they were providing care to an elderly individual, 347 (8%) provided care to a child under 18 years of age who was not their own.

According to the survey, of the 1,277 County employees who provided caregiving assistance to an older adult, 149 (12%) also reported providing care to a child under 18 years of age who was not their child (i.e. a grandchild, niece/nephew). Multigenerational caregivers are often known as the "sandwich generation" because they are caring for generations above and beneath themselves .

- Of the 149 multi-generational caregivers, 80 (54%) provided care for one child, 44 (30%) provided care for two children, and 25 (17%) provided care for three or more children who were not their own.
- Of the 149 multi-generational caregivers, 77 (52%) were caring for grandchildren, 19 (13%) were caring for a niece or nephew, and 103 (69%) were caring for some other child. (Note that percentages in parenthesis do not add to 100% because some employees were providing care for more than one child. For example, an employee may have been providing care for both a grandchild and a niece or nephew).

## FINDING UNMET CAREGIVER NEED IN ORANGE COUNTY

Finding unmet caregiver need in Orange County is complicated by the ethnic and linguistic diversity of the region.

The concept of "caregiver" is not universal and planning at a regional level should take into consideration different responses to older adult need.

The Multilingual Senior Needs Assessment afforded a rare opportunity to determine a level of unmet need for caregiving among ethnic and language groups. The survey found no differences among different ethnic groups when the primary language of the older adult was English. Differences in responses were more apparent when comparing English, Spanish, and Vietnamese speakers.

Older individuals (age 62+) were asked to evaluate their ability to manage independently in fourteen areas of daily activity. Family members of 88 of the older respondents were asked to rate the older respondents on the same fourteen areas. Respondents and their families spoke English, Spanish or Vietnamese.

Older respondents were asked whether they found each activity to be "Not difficult," "Somewhat difficult," "Very difficult," or "Unable to do."

Doing heavy housework and walking were rated as the most difficult activities by those in need of care.

### Senior Functional Self-Assessment

Activity	Not difficult	Somewhat difficult	Very difficult	Unable to do
Eating	93.4%	4.7%	1.4%	0.2%
Bathing	93.3%	5.0%	1.0%	0.7%
Dressing or undressing	93.6%	5.0%	1.1%	0.3%
Walking	74.8%	18.5%	5.3%	1.4%
Getting in and out of bed	91.8%	7.5%	0.5%	0.3%
Getting to the bathroom	94.4%	4.4%	1.0%	0.3%
Preparing meals	90.1%	6.4%	1.1%	2.4%
Shopping for personal items	86.4%	9.2%	2.3%	2.1%
Medication management	93.5%	4.7%	1.4%	0.5%
Managing Money	90.5%	7.1%	1.6%	0.8%
Using the telephone	95.3%	3.5%	1.0%	0.2%
Doing heavy housework	56.4%	19.7%	8.7%	15.2%
Doing light housework	87.6%	7.7%	1.4%	3.4%
Transportation ability	83.0%	6.4%	3.1%	7.5%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

Families and seniors did not always agree on the senior's ability to perform activities. Eighty-eight family members of seniors agreed to be interviewed in the Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001. In most cases, families and seniors agreed on the amount of help the senior needed. Importantly, in more than 10% of every activity other than "dressing and undressing" and "using the telephone," family members felt that the older adult needed more assistance than the older adult reported needing.

"Shopping for Personal Items" and "Medication Management" were activity areas where the older adult and family member of every language disagreed significantly with each other. In both areas the older respondents felt capable of performing at a higher level than indicated by the family members. But in the area of "Shopping for Personal Items," family member responses differ according to primary language.

**Senior Assessment vs Family Assessment**

Daily Activity	Fam<	Fam=	Fam>
Eating	8%	79.5%	12.5%
Bathing	4.5%	84.1%	11.4%
Dressing or Undressing	2.3%	90.0%	6.8%
Walking	10.5%	75.6%	14.9%
Getting In and Out of Bed	4.5%	84.5%	11.4%
Getting to the Bathroom	2.3%	86.2%	11.5%
Preparing Meals	8.0%	75.0%	17.0%
Shopping for Personal Items**	4.6%	66.3%	29.1%
Medication Management**	10.55%	69.8%	19.8%
Money Management	8.2%	74.1%	17.6%
Using the Telephone	4.7%	87.2%	8.1%
Doing Heavy Housework	22.1%	37.2%	40.7%
Doing Light Housework	6.8%	83.0%	10.2%
Transportation Ability	12.5%	64.8%	22.7%

\* Fam < means the family member felt the older adult needed less assistance

Fam = means the family member felt the same as the older adult

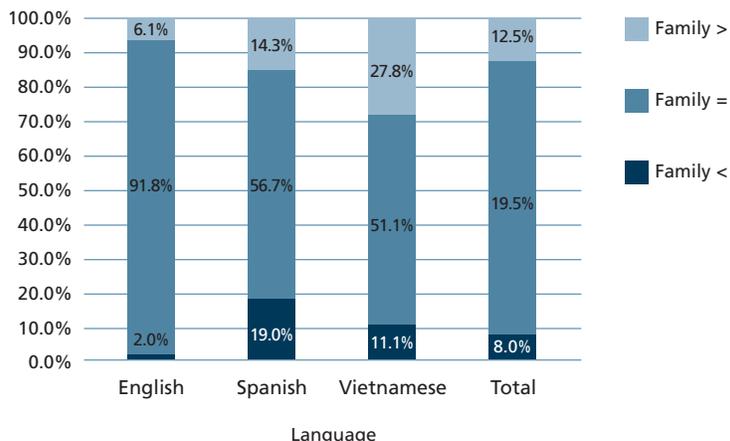
Fam > means the family member felt the older adult needed more assistance

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

\*\* In these two areas there were significant differences between the responses of all family members and the respondents.

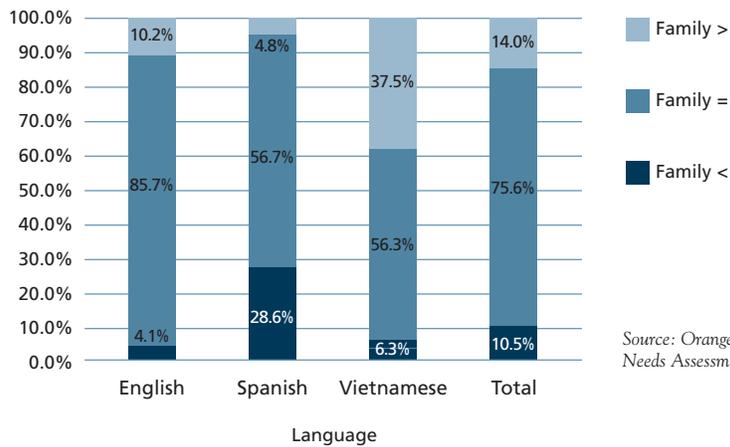
Eight of the activities of daily living showed significant differences in response by language. Families of English speakers agreed with the evaluations of the older adults more than either Spanish or Vietnamese speaking families.

**Activity: Eating**



Vietnamese speaking families felt that a significantly large number of older adults surveyed had more problems eating than did the older relatives themselves, while the Spanish speaking families felt that their older relatives overestimated their problems eating. Both Vietnamese speakers and Spanish speakers showed more variability than English speakers when evaluating how their older relatives ranked their ability to perform this activity.

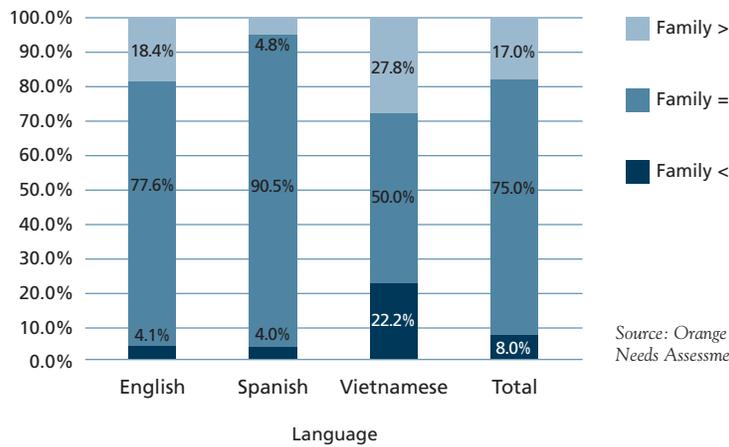
**Activity: Walking**



Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

A look at the activity "Walking," shows a different pattern. English language families again have the highest agreement rate with their older adult relatives. A significant number of Spanish speakers felt that their older adult relatives can walk better than the relatives reported, while Vietnamese families felt that their older relatives needed more assistance walking than the relatives reported.

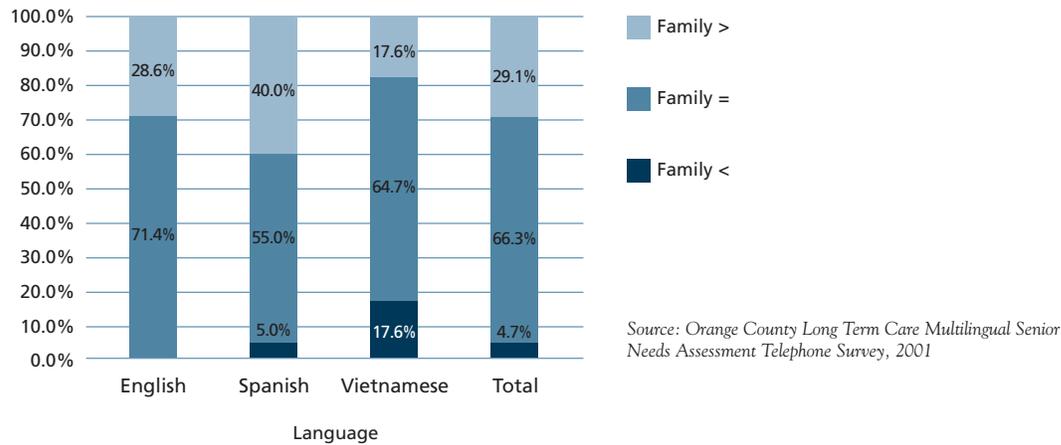
**Preparing Meals**



Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

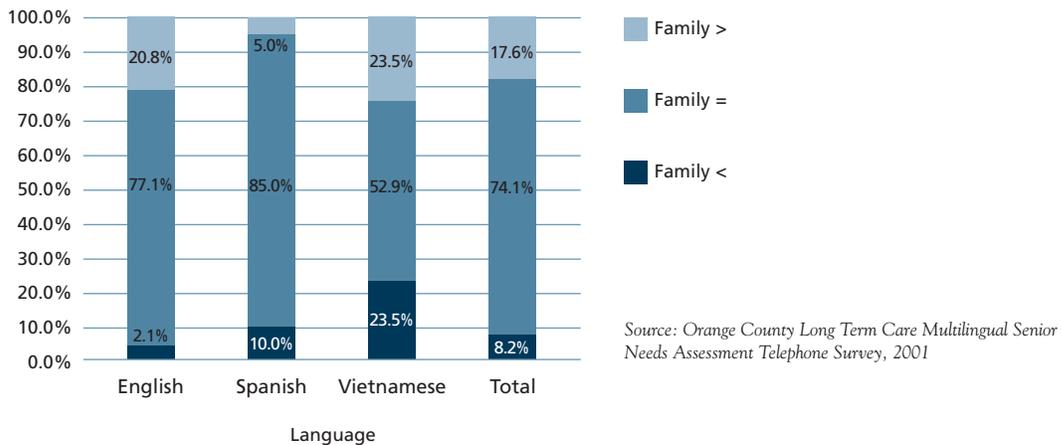
Families within different language groups also differed significantly in how they viewed their older relative's ability to prepare meals. Spanish speakers had the most agreement between the older adult and family member. Vietnamese speakers had the most disagreement; however, Vietnamese families split almost equally on whether their older relative needed more assistance or less assistance than reported. English speakers tended to have a significant number of families who felt that the older adult needed more help preparing meals than reported.

**Shopping For Personal Items**



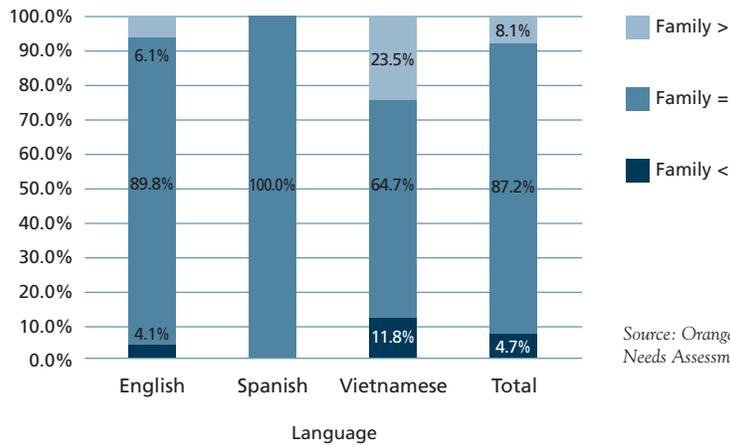
The three language groups differ on the response to "Shopping for Personal Items." Although 71.4% of English speakers agreed with their older relatives, a relatively large 28.6% felt that their older relative needed more assistance than the relative reported. Spanish speakers had the least agreement with older relatives. Only a handful (5%) thought the older relatives could use less assistance. 40% felt that their older relatives could use more assistance than the relatives reported. There is no clear pattern among the Vietnamese speakers; almost 65% agreed with their older family members, but the remaining responses were split equally among relatives who felt the older adults needed more assistance and those who felt they needed less.

**Money Management**



Families in different language groups differed in agreement with their older relatives on the elder's ability to manage money. A significant majority of the English (77.1%) and Spanish (85%) speakers agreed with the older family member regarding the older relative's ability to manage money. About one-fifth (20.8%) of the English speakers felt that their relatives could use more assistance with money management. On the other hand, 10% of the Spanish speakers felt that their older relatives underestimated their ability to manage money. Equal numbers (23.5%) of the Vietnamese family members felt either that the older relative did not need or needed more assistance. Only 52.9% agreed with the older relative among the Vietnamese speakers.

### Using the Telephone

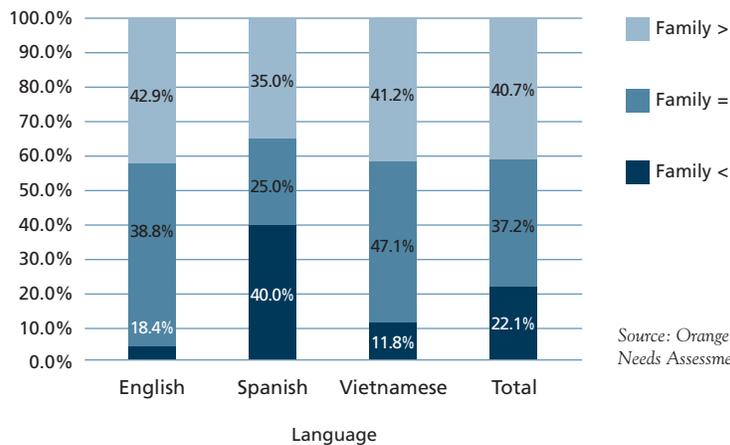


Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

Using the telephone had not only language differences but also gender differences. Family members agreed more with older female relatives (89.1%) than older male relatives (83.3%), but the real difference in the responses is in the direction of the disagreements. Family members said that 10.9% of the female older relatives needed more help than reported, but that 13.3% of males need less help than they had reported.

Spanish speaking family members agreed 100% with older relatives regarding their ability to use the telephone. There was also high agreement among English speakers and their older relatives (89.8%). Vietnamese family members agreed with their older family members only 64.7% of the time. Almost one-quarter of the family members (23.5%) felt that the older relatives could use more assistance than the older relatives reported needing.

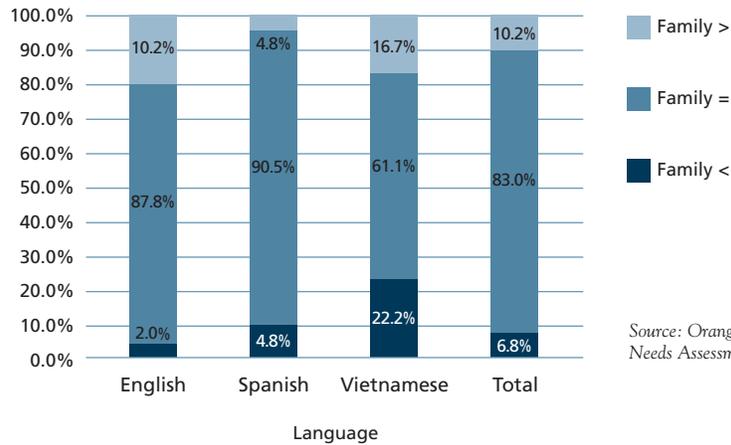
### Doing Heavy Housework



Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

One of the most interesting results in the survey is the comparison of family responses to older adults in the "Doing Heavy Housework" activity. Family members in every language group disagreed with the older adult respondents more than half the time. Among Spanish speaking relatives there was agreement only 25% of the time. Most of the time English and Vietnamese family members felt the older adults needed more assistance than the older respondents reported. Spanish speaking family members were almost evenly split between saying that their older adult respondents needed more or less assistance than reported.

**Doing Light Housework**

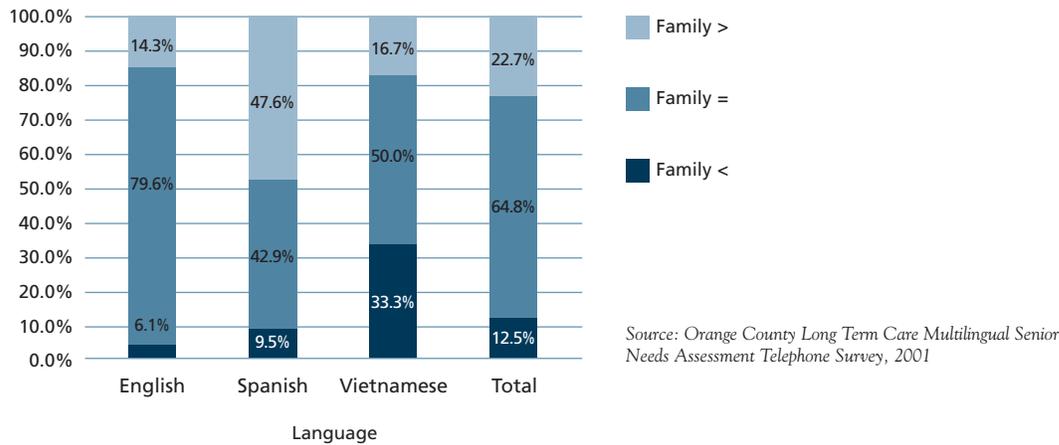


Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

Family members significantly disagreed with older adults in both age and language for the "Doing Light Housework" activity. Family members tended to agree more with younger elders (Mean Age: 68.6 years). Older adults whose families said they need more assistance with light housework were the oldest (Mean Age: 76.2 years). Older adults whose families thought they could use less assistance than the respondents themselves did were not significantly different in age from those with whom family members agreed (Mean Age: 70.2 years).

A large percentage of Spanish speaking (90.5%) and English speaking (87.8%) family members agreed with their older relatives regarding their ability to perform light housework. Only 4.8% and 2.0% of the Spanish and English speaking family members respectively felt that their older relatives were capable of doing with less assistance than reported. 22.2% of Vietnamese family members felt that their older relatives were capable of functioning with less assistance. 16.7% of Vietnamese families felt that their older relatives needed more assistance than the elders reported, compared to 4.8% and 10.2% in the Spanish and English speaking families.

### Transportation Ability



"Transportation Ability" is the last activity where significant differences were found among the family member responses in the three languages. Significantly more English speakers (79.6%) agreed with their older adult relatives regarding the relative's need for transportation assistance. Spanish speakers and Vietnamese speakers agreed with their older relatives only 42.9% and 50% of the time respectively. 47.6% of Spanish speaking family members felt that their older relatives needed more assistance with transportation than the older relatives reported. Only 14.3% of English speaking family members and 16.7% of Vietnamese family members felt that their older adults needed more assistance. One third of the Vietnamese respondents felt that their older relatives needed less assistance with transportation than the older relative reported. English and Spanish speakers were 6.1% and 9.5% respectively in reporting that their relatives needed less assistance with transportation.

The above differences in language, gender and age when comparing family and older adult responses are important for community planners when planning caregiver services. Areas of general agreement between individuals within specific language groups show areas where family members can be of valuable assistance in guiding older relatives to services. Conversely, areas where family members have significant disagreement in their perceptions of an elder's ability to perform activities of daily living can show planners areas where multigenerational conflict may be expected. It is worth noting here that in most instances there was greater disagreement between seniors and family members among the Vietnamese respondents than occurred in the other ethnic groups. This outcome may warrant more analysis from cultural specialists than is available at the present time.

## CAREGIVING AND DEMENTIA

Of all the physical and mental problems that confront aging individuals, possible loss of memory through Alzheimer's disease or other dementia is the most frightening.

Over the last century Americans have added almost 40 years to life expectancy. With the increase in lifespan has come an increase in geriatric illnesses such as Alzheimer's disease. The Multilingual Survey recorded responses of Orange County seniors regarding Alzheimer's disease and caregiving. When asked whether someone in the home has Alzheimer's disease, 5.7% responded "yes." In over one-third (33.9%) of the households that responded "yes," the respondents themselves stated that they had Alzheimer's disease.

Again, respondents differed by primary language. Vietnamese respondents made up more than half of the respondents who have Alzheimer's disease. English speakers were more likely to have someone with Alzheimer's disease living in the home. Only one Spanish speaker responded "yes" to the question; that individual had Alzheimer's disease.

#### Care Receivers: Level of Care

Type of Care Provider	% Receiving Care				
	English	Spanish	Vietnamese	Other	Total
Spouse	26%	22.1%	9.7%	37.1%	21.1%
Other Relative	31.2%	71.8%	82.6%	44.4%	51.6%
Friend	6.1%	1.4%	1.9%	11.1%	4.4%
Agency Volunteer	4.6%	0.7%	0.3%	0.0%	2.7%
Paid Worker	32.1%	4.0%	5.5%	7.4%	20.1%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

Only the English speakers stated that they had no caregiver at this stage of the disease. The Spanish speaker had a paid worker. The Vietnamese respondents had a variety of caregivers. Only 17% were cared for by a spouse; 50% were cared for by an adult child, one-fourth were cared for by paid workers, and slightly over 8% were cared for by siblings.

Of the individuals who stated they lived in the home of someone else who has Alzheimer's disease, 52.9% of the English speakers and 60% of the Vietnamese speakers stated that they were the main caregivers of the individuals with the disease. No Spanish speakers or other language speakers identified someone else with Alzheimer's disease in the household.

## KNOWLEDGE OF AVAILABLE SERVICES

Over half of the caregivers surveyed receive some formal support with caregiving.

In general they express a need for increased access to some services, with the greatest needs being in the areas of housekeeping, support groups and respite care. A significant proportion expressed no need for services at the time of the survey.

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Paid Worker	32.1%	4.0%	5.5%	7.4%	20.1%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

### Caregiver Services

Services	Support Group	Respite Care	Help with Transportation	Help with Housekeeping	Legal Services	Funds to purchase services	None
Caregiver Receives	5.1%	10.3%	7.7%	15.4%	2.6%	2.6%	41.0%
Caregiver Needs	15.4%	15.4%	7.7%	17.9%	2.6%	7.7%	25.6%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

### Services for the Care Receiver

Services	Care Receiver Has	Care Receiver Needs
Occasional Paid Worker	10.3%	12.8%
Adult Day Care	7.7%	10.0%
Regular In-home help w/ dressing, etc.	7.7%	12.8%
Transportation services	5.1%	10.0%
Legal services	2.6%	5.1%
Financial support to pay for services	2.6%	10.0%
Geriatric case management	5.1%	5.1%
Regular medical care	17.9%	35.0%
Regular psychiatric/mental health care	7.7%	5.1%
Other	7.7%	10.0%
None	35.9%	45.0%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

Regular medical care is the most important need for individuals receiving care, far exceeding the next categories, "occasional paid worker" and "regular in-home help." Services are paid for by several sources, most often by Medicare/Medi-Cal (70%) and In Home Supportive Services (IHSS). Other sources of payment for services include health insurance (30%), personal savings (10%), family resources (10%), long-term care insurance (10%), and Veteran's Administration (8%).

While a variety of services are available for Orange County residents, most respondents to the Multilingual Survey were unaware of these resources.

### Awareness of Caregiver Resources

Knowledge of:	Adult Day Care	Alzheimer's Association	Orange Caregiver Resource Center	Geriatric Care Manager
Very Familiar	7.4%	4.5%	1.2%	6.8%
Somewhat Familiar	15.4%	12.2%	5.0%	15.1%
Somewhat Unfamiliar	12.9%	9.2%	4.6%	6.7%
Not at all Familiar	42.1%	72.9%	89.2%	71.3%

Source: Orange County Long Term Care Multilingual Senior Needs Assessment Telephone Survey, 2001

Respondents were more likely to have heard of Adult Day Care than any of the other resources. Adult Day Care Centers recruit heavily in communities and are often sponsored by cities or other governmental agencies. The Orange Caregiver Resource Center is the least known, although it has been in place as a State mandated program for almost 20 years.

In 2002 the Office on Aging recognized the need to develop a guide of services for grandparents who provide multigenerational care to family members. The Orange Caregiver Resource Center attempted to survey 80 public service agencies regarding services to grandparents. Twenty agencies responded. Although that study is in the analysis process, early findings indicate that the agencies favor a central resource data base that can be accessed by every agency as the need arises.

## CONCLUSIONS

As in all parts of the country, families in Orange County provide most of the care to older adults who can no longer manage to care for themselves.

The amount of care given depends on many factors, including family resources (in manpower, living space and finances), access to services (proximity and knowledge regarding services), and level of incapacitation experienced by the older adult. The data show that family caregiving can be physically and emotionally hazardous to the caregiver.

**Our knowledge of how the medical and mental health communities reach out to caregivers is limited. This knowledge gap should be closed to facilitate referrals for caregivers to appropriate resources.**

Orange County residents are more likely than other U.S. residents to be multigenerational caregivers. Resources for grandparents with legal guardianship are the same as those for parents with similar personal resources.

**The most obvious gap in services for multigenerational caregivers is that no resource addresses the complexity of this new phenomenon in family structure.**

The Orange Caregiver Resource Center and the Alzheimer's Association provide respite and mental health resources for caregivers with the daily responsibility of caring for a brain impaired or otherwise frail older person. Adult Day Health Care Centers provide places where frail individuals can be maintained during the work day.

**The most obvious gap in service for caregivers with the daily responsibility for frail non-mentally impaired older adults is the patchwork of respite for caregivers who may need respite from both work and caregiving.**

With regard to caregiver issues, employees of the County of Orange may be considered reflective of the wider community of workers in Orange County. Given the current economic climate in both the governmental and private economic sectors, caregiving responsibilities may have an increasingly negative impact on the workplace.

**Human resource offices that make caregiver resource referrals available will be cost savers for employers and employees alike.**

Orange County is fortunate to have data available for older adults by primary language. Researchers have found that grouping information by ethnicity alone does not yield differences that can be used profitably by planners. However, grouping information by primary language generates measurable differences in need, utilization of services, caregiver responsibilities, and unmet need. This is not surprising because language embodies cultural differences. People who maintain a primary language other than American English often maintain cultural responses to changes that differ from those common to English speakers. Older adults with a primary language other than English tend to differ from their families when evaluating their ability to perform daily tasks more than English speakers. For instance, English speaking family members generally agreed with their older relatives in all areas except the ability to do heavy housework. In Spanish speaking households there was disagreement between families and older adults in ability to walk, eat, shop, provide personal transportation, and do heavy housework. From Vietnamese speakers, there was significant disagreement in every area.

Service providers most often depend upon family members to relay the needs of older adults who have limited English language ability. These results show that non-family members may be better able to relay the perceived need of individuals with limited English ability.

Family members are often bilingual and have become more bi-cultural than their older adult family members. In the process of becoming bi-cultural, they may confuse the importance of displaying cultural ideals with an agency's actual goal of providing the needed service. Licensed interpreters are trained not to make subjective changes in translation and may be useful, especially in first encounters.

**Planning services for older adults who speak a primary language other than English must take into consideration whether the needs of client are being appropriately relayed by family members. English speaking family members tend to most clearly understand the need levels of their older adult relatives.**

In addition to level of familial understanding of an older adult's needs, utilization of caregiver services appears to be significantly different by language. Planners must be cautious when using utilization outcomes in planning. Utilization rates may be as much a function of cultural propensity as availability of and access to services for a language group. More research is needed in this area.