

California's
Caregiver Resource Center System

ANNUAL REPORT

*The Comprehensive Act for Families and Caregivers
of Brain-Impaired Adults*

**Chapter 1658, Statutes of 1984, as amended by Chapter 775,
Statutes of 1988 and Chapter 7, W&I code, Section 4362 et al., 1992**



July 1, 2003 through June 30, 2004

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ANNUAL REPORT

FISCAL YEAR 2003-2004

*The Comprehensive Act for Families and Caregivers
of Brain-Impaired Adults*

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This Annual Report was prepared by the Statewide Resources
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EXECUTIVE SUMMARY

This report addresses the progress of the *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults*¹ between July 1, 2003 and June 30, 2004. This time period marks the nineteenth year of implementation of this statute demonstrating California's commitment to serving family caregivers. The report profiles family caregivers and the adults with cognitive impairment for whom they care and includes: 1) the cost and amount of each service provided; 2) an assessment of the nature and extent of the demand for services that provide caregiver support; 3) an analysis of the program in deterring the institutionalization of adults with cognitive impairment; and 4) recommendations for ensuring that unmet needs of cognitively impaired persons and their families are identified and addressed with appropriate programs and services.

The Department of Mental Health (DMH) established the Caregiver Resource Centers (CRCs) statewide program in 1984. The CRCs were legislatively mandated to assist families who provide long-term care for loved ones afflicted with Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury, and other chronic or degenerative cognitive disorders that strike adults. At the end of Fiscal Year (FY) 1988-89, eleven non-profit centers were designated, covering all geographic regions in California. Additionally, the law established a Statewide Resources Consultant (SRC) to operate a statewide information and technical assistance clearinghouse on cognitive impairment, and assist the DMH by providing consultation, training, research, technical, and program assistance to the CRCs.

The total contract awarded to the eleven resource center sites and the SRC was \$11,747,000 in FY 2003-04. During FY 2003-04, some of the CRCs also received funding from the National Family Caregiver Support Program (NFCSP) administered through California's Department of Aging and thirty-three Area Agencies on Aging. Utilizing NFCSP funds, the CRC system provided additional services to caregivers in the following areas: gaining access to supportive services; information about available services; individual counseling; organization of support groups; caregiving training; respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and supplemental services to complement the care provided by the caregivers.²

During fiscal year 2003-04:

- Client intake remained stable from FY 2002-03 (changed from 7,581 to 7,681). Approximately 55% of those completing intake went on to be assessed for CRC services.
- Client follow-up information and referral increased 5% from FY 2002-03, and client reassessment and family consultation increased 6% and 2% respectively over the same period.

¹ Chapter 1658, Statutes of 1984, as amended by Chapter 775, Statutes of 1988 and Chapter 7, W& I Code, Section 4362, et al., 1992.

² This report only includes service figures for Chapter 1658 funds, i.e. detailed service data on NFCSP funds are not included in this report.

- The total number of individuals receiving at least one CRC service remained stable from FY 2002-03 (changed from 16,379 to 16,562) while the number of families receiving CRC respite assistance was also stable, changing from 1,712 to 1,735 over the same period.
- Most family caregivers received an average of 5.7 hours of caregiver support services³ beyond basic information and comprehensive assessment, excluding respite assistance.
- The annual expenditure for respite care voucher services at the 11 CRCs was \$2,987,275 or an average of \$3,875 per family caregiver who received respite per year. The average monthly cost per family caregiver was \$344, of which \$323 was provided by the CRCs. The average monthly cost for a Medi-Cal patient (\$3,423 in FY 2002) in a California skilled nursing facility is *10 times* the average monthly cost of CRC respite services. The average monthly private pay nursing home cost is over *13 times* (\$4,477 in 2004) the average monthly cost of CRC respite services.
- Respite is a primary need for caregivers. The average client wait time for CRC respite assistance increased by two months to a 25-month wait. At the end of FY 2003-04, 4,910 family caregivers were on respite waiting lists at CRCs in California.

Key findings from the CRC statewide assessment database⁴ are as follows:

- The typical caregiver is 61 years old. *Fifty percent* of caregivers are 60 years of age or older; *twenty percent* are at least 73 years old or older.
- The family caregiver is most likely to be a female (77%), typically a daughter or wife.
- Caregivers provide an average of 12.4 hours of care per day – seven days per week – more than a full-time job.
- Caregivers receive only an average of 1.5 hours of help per day from family or friends. Close to 6 out of 10 (62%) caregivers feel they receive “far less” and “somewhat less” help from family or friends than they need. And 22% say they get “no help.”
- Almost two-thirds (60%) of caregivers reported feeling “depressed” or “anxious,” while 44% were scored as “depressed” using the Center for Epidemiological Studies Depression Scale (CES-D). Overall, 59% on the Adapted Zarit interview scored at high burden levels.

The most frequently expressed need among caregivers at intake was for general information, followed by emotional support, and respite. For caregivers who went on to receive the more in-depth CRC assessment, respite care was the most frequently identified unmet need, followed by emotional support and basic information. While there are some difficult cases where it may not

³ Includes one or more of the following: family consultation, counseling, legal assistance, support group, caregiver retreat, education/training, and psychoeducational group.

⁴ Data are from the CRC Uniform Assessment Database 2003. See the Methodology section for more detailed information.

be possible for family caregivers to keep their loved ones at home, information and support services help to deter the institutionalization of the care receiver.

The following recommendations address the needs of California's caregivers of adults with brain impairments:

1. Increase the number of caregivers receiving core CRC services through community-based collaborations and widely disseminated information and education campaigns targeting underserved caregivers, particularly minority and rural caregivers.
2. Promote public policy that advances the consumer-directed model of care for all caregivers and care receivers and supports the prevention, diagnosis, treatment, and cure of brain impairing conditions.
3. Improve assistance to working and isolated caregivers via technology, e.g., increase the number of caregivers using the internet-based Link2Care program.
4. Explore establishing liaisons with the private sector to provide caregiving resources to caregivers working outside the home.
5. Work cohesively with statewide groups addressing the need for appropriate and affordable long-term care options for care receivers and their family caregivers through public awareness and the development of affordable, accessible, and culturally appropriate long-term care services.
6. Identify viable program options for traumatic brain injury (TBI) caregivers and their loved ones.
7. Carry out CRC research to: 1) measure and analyze the impact of cognitive disorders on family and caregiver well being, and (2) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers.
8. Enhance local partnerships with AAAs to expand family consultations, counseling, and respite services to caregivers using National Family Caregiver Support Program funds.

ISSUE

The demand for and number of informal caregivers – those who provide care without pay – increases as California’s population grows larger and older. The recent California Statewide Survey of Caregivers found that 16% of all California households contain at least one caregiver for someone age 50 or over. Of those caregivers surveyed, 44% assist someone who has mental health or behavior problems. Cognitively impaired care recipients require more time of their caregivers. Caregivers of recipients with these problems also are more likely to feel that they are not receiving enough assistance from paid service providers.⁵ Although the primary needs of all caregivers are similar (e.g., the need for basic information, respite care, and emotional support), caregivers of cognitively impaired adults have special needs. The cognitive, behavioral, and psychological changes associated with brain impairment in individuals with Alzheimer’s disease, stroke, Parkinson’s disease, Huntington’s disease, and traumatic brain injury often result in difficulties with activities of daily living (e.g., bathing, eating, and dressing), memory functions, and emotional and mental well-being. In turn, these difficulties promote tremendous physical and emotional burnout, financial stress, and self-sacrifice among family caregivers, exacting enormous tolls on families, communities, and society. To cope, caregivers require a range of caregiving services designed to provide support throughout the caregiving experience.

To address the needs of adults with brain impairments, a population traditionally outside the mainstream service delivery system, Chapter 1658, Statutes of 1984, was enacted. This legislation, which created statewide support services for the growing population of family caregivers caring for individuals with cognitive impairment, identified the informal caregiver as the “client.” In particular, the legislation provided critical support for caregivers of adults with Alzheimer’s, Parkinson’s, stroke and other cognitive diseases and disorders by addressing family caregiver’s shared common concerns and challenges: isolation, emotional distress, lack of information and community resources, and drastic changes in family roles.

The *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults*, Chapter 1658 legislation, as amended by Chapter 775, 1988, and Chapter 7, W&I Code, Section 4362 et al., 1992, directed the Department of Mental Health (DMH) to establish a statewide system of Caregiver Resource Centers (CRCs) in California. The centers were designed to facilitate a single point of entry for caregivers within each CRC service region with appropriate programs and services for families and caregivers of adults with cognitive impairment.

To promote the goals of the legislation, the law also established a Statewide Resources Consultant (SRC) to do the following: serve as the centralized information and technical assistance clearinghouse on caregiving and cognitive impairment; provide consultation, training and technical assistance to the CRCs; conduct conferences, social policy research, and training programs to enhance the quality of care and treatment of brain-impaired adults; assist the State in coordinating with other State initiatives; and aid the DMH in evaluating the effectiveness of the CRC system.

⁵ Center for the Advanced Study of Aging Services. (January 2003). Scharlach, A. Sirotnick, B. Bockman, S. Neiman, M. Ruiz, C. Dal Santo, T. *A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers*. Retrieved October 1, 2003 from University of California at Berkeley Center for Social services Research site: http://cssr.berkeley.edu/aging/pdfs/FamCareProfile_Entire.pdf

To appropriately assess the effectiveness of the CRCs, the enabling legislation requires the Department, in consultation with the SRC, to report annually to the Legislature on the following:

- 1) The costs and amount of each type of service provided.
- 2) An assessment of the nature and extent of the demand for services that support caregivers, and an evaluation of their success in meeting this demand.
- 3) An analysis of the program in deterring the institutionalization of brain-impaired adults, allowing caregivers to maintain a more normal routine and promoting the continuance of quality care for adults with cognitive impairment.
- 4) Recommendations for ensuring that unmet needs of cognitive-impaired persons and their families are identified and addressed with appropriate programs and services.

This report addresses these requirements and provides information on the eleven CRCs for the period July 1, 2003 through June 30, 2004.

BACKGROUND

History

The CRC system began as a grass roots community effort more than a quarter century ago to address the myriad of problems associated with adult onset cognitive disorders. The compelling story of one San Francisco woman caring for her husband with Alzheimer's disease alerted policy makers and service providers to the scarcity of available residential placements and the lack of supportive services for family caregivers.

A San Francisco task force was convened in 1976 to investigate the chronic care problems of middle-income Americans with irreversible cognitive impairment. Two years later, DMH awarded a special grant to the task force, then known as the Family Survival Project (later changed to *Family Caregiver Alliance*), to conduct a needs assessment of the San Francisco community to determine the number of adults with cognitive impairments and available services.

In 1980, under Chapter 1058, Statutes of 1979, the DMH contracted with Family Caregiver Alliance to establish a pilot program to test the effectiveness of services to families and caregivers of adults with cognitive impairment. The project confirmed the package of core services developed in the pilot program were successful in assisting families and caregivers of persons with all forms of adult-onset cognitive impairment in coping with their caregiving responsibilities and avoiding or delaying the need for skilled nursing or institutional care of the care receiver.

In 1984, Chapter 1658 (AB 2913, Agnos) was signed by the Governor which: 1) phased-in development of resource centers, based on the successful model of Family Caregiver Alliance's pilot program, in each major geographic region of the State that, together, would provide a single-entry information network; and 2) established the SRC role under contract to the State to implement aspects of the new law that were statewide in nature.

In FY 2003-04, the total contract award to the eleven resource center sites and the SRC was \$11,747,000.00. See Appendix A, Site Distribution List, for a listing of site names, host agencies, and counties covered.

Overview

Caregivers of adults with cognitive impairment face daunting and complex problems, which dramatically alter their physical, emotional, and financial health. To address these multi-faceted needs, the CRCs provide a single point of entry for families. Respite, counseling and emotional support, education, and training are provided to caregivers from the moment of first contact until the family no longer requires assistance, often many years later. Of equal importance, CRCs work closely with a full range of community organizations and services to effectively address the diverse needs of the caregivers.

OBJECTIVES

The service components provided by the resource centers include the following:

- **Information, advice, and referral;**
- **Uniform Assessment of caregiver needs;**
- **Long-term care planning and consultation;**
- **Legal and financial consultation;**
- **Mental health interventions** (such as counseling, support groups and psychoeducational groups);
- **Education and training programs** (such as workshops);
- **Respite care services** through the flexible and creative use of local resources including: home care, adult day care services; transportation; and temporary placement in a residential facility; and
- **Online service for education, information and support (Link2Care).**

Additionally, CRCs are mandated to:

- Provide centralized access to information about, and referrals to, local, state, and federal programs;
- Coordinate with other organizations serving adults with cognitive impairment, their

families and caregivers;

- Assist in the identification and documentation of service needs;
- Promote the development of necessary community programs regionally; and
- Cooperate with the SRC and the DMH in the implementation of this program.

As required under the law, the DMH also maintains a contract with the SRC at Family Caregiver Alliance to:

- Serve as the Statewide Information and Technical Assistance Clearinghouse on adult-onset cognitive impairment and caregiving issues;
- Provide coordination with other statewide organizations, which serve adults with cognitive impairment, their families and caregivers;
- Develop and conduct training appropriate for families, caregivers, service professionals, advocacy and self-help family and caregiver support organizations; and educational institutions;
- Conduct conferences to assist families, caregivers, service professionals, advocacy organizations, educational institutions, business associations, community groups, and the general public;
- Assist in identifying and securing increased federal financial participation and third-party reimbursement;
- Conduct social policy research;
- Assist in data collection; epidemiological research; and development of uniform terminology and data collection;
- Assist the DMH in establishing criteria for and in selecting the resource centers; and
- Provide technical assistance and consultation to the resource centers for service and program development.

METHODOLOGY

Information and data were collected for this report from three sources: 1) CRC quarterly data collection on caregivers, care receivers, services and expenditures via the CRC uniform Services Automation System; 2) CRC Semi-annual Progress Reports; and 3) CRC uniform caregiver assessment data.

1. ***CRC Services Automation System*** and ***Caller/Caregiver Provider Tracking System (CCPTS)*** include data collection reporting requirements on all clients served, date of service, service mix, and case status. Major data components used in this report include:
 - a. **All individuals completing the CRC intake process** (e.g., the total number of callers, caller ethnicity and a summary of the callers' identified needs);
 - b. **The number of family caregivers served** and average service mix during the fiscal year;
 - c. **The units of service** (i.e., amount of service) **for each service** provided to family caregivers during the fiscal year;
 - d. **Expenditures for voucher services** as reported in the CRC Services Automation System; and
 - e. **Co-payments for respite services** paid by family caregivers.
2. ***Semi-annual Progress Reports*** include CRC progress on staffing and administrative functions; the documentation of any new unmet needs identified regionally; and activities and accomplishments in three strategic plan objectives.
3. ***Family caregiver assessment data*** are obtained using a uniform, comprehensive assessment instrument to determine the well being of family caregivers who contact the CRCs for help beyond basic information. CRC uniform assessment data from the 2003 calendar year is presented in the Findings Section. (This is calendar year data, not Fiscal Year data.)

FINDINGS

This section of the report provides findings from all three key sources of information to present a detailed and accurate description of caregivers served by the CRCs, the persons they care for, and the services provided to these individuals through the CRCs. First, a descriptive profile of care receivers and caregivers is presented. Second, findings, as specified in the legislation, addressing the cost and amount of services provided, the demand for respite care, the effectiveness of the program in delaying or deterring institutionalization, and the identification of unmet needs and service gaps for care receivers and their family caregivers in California are reported (Tables and Figures used for this report are presented on pages 25-51). Last, an outline of the CRC System Strategic Plan Goals is presented with accomplishments for FY 2003-2004.

*Profile of Care Receivers and Family Caregivers*⁶

A. Selected Care Receiver Characteristics:

Care receivers are typically older, ranging in age from 18 to 105 years old, with an average age of 78. *Ninety percent* of care receivers are age 60 and older. *Eighty-five percent* are at least 65 years of age; *68%* are 75 years of age and older; and *30%* are at least age 85.

Care receivers are more likely to be female (*55%*) than male (*45%*). They generally live with their spouse only (*46%*), or with other relatives (*39%*). Comparatively few care receivers live alone (*9%*) or in nursing homes (*1%*) when the caregiver first calls the CRC for assistance.

The median annual household income range for the care receiver population in 2003 was between \$20,000 and \$39,999, clearly below California's median income in 2003 of \$50,220.⁷

Sixty-two percent of care receivers have a dementing illness, principally Alzheimer's disease (*29%*), but also Parkinson's disease (*8%*), Huntington's disease (*0.5%*), and other dementias/degenerative diseases (*31%*). *Twenty-two percent* had a stroke, *3%* are traumatic brain injury survivors, and *3%* have brain tumors or other non-degenerative disorders. The vast majority of care receivers (*86%*) have a confirmed diagnosis.

Fifty-two percent of care receivers experienced the onset of a disease/disorder less than two years ago. *Thirty-nine percent* of care receivers experienced the onset of disease/disorder within a range of three to ten years. *Nine percent* of the population has lived with their cognitive disease/disorder for 11 years or longer.

Problem Behaviors Associated with Brain Impairment:

These care receivers have particularly heavy care needs. As reported by their caregivers, they average thirteen memory and behavior problems, commonly related to the individual's cognitive

⁶ CRC Uniform Assessment Database 2003 (N = 5,023 family caregivers). Note: Past reports cover full calendar year from Jan. 1st to Dec 31st. Due to introduction of new data management system the period covered in this report is Jan 1st - June 30th. Past annual reports show little variation from year to year.

⁷ U.S. Census Bureau, America Community Survey, California, 2002.

deficits. Those problems most often reported as bothering or upsetting and which rated as “very much” or “extremely” were: Appears sad or depressed; Arguing, irritability, and/or complaining; Appears anxious or worried; Waking you or others at night; and Asking the same question over and over.

There were an average of nine functional problems related to inability to perform daily tasks that were reported most often. Those problems reported at the highest frequency were: Taking medications, Managing money, Preparing meals, Performing chores, Staying alone, Bathing, and Dressing.

B. Selected Caregiver Characteristics:

The average caregiver served at California's CRCs is a 61-year old female who has been caring for her father or husband with Alzheimer's disease for one to two years.

Caregivers are largely female (77%), and range in age from 18 to 97 years with an average age of 61. *Fifty percent* of the caregivers are 60 years of age or older. *Twenty percent* are 75 years of age and older. *Twenty-three percent* are between the ages of 36-50 years.

Caregivers served by CRCs are typically spouses (46%), while 40% are adult children and 14% have another relationship to the care receiver. Family caregivers are most likely to identify themselves as the "primary" caregiver (91%) and to live with the care receiver (69%).

The majority of family caregivers served by the CRCs are white (76%), 10% are Hispanic, 8% are African American, 4% are Asian/Pacific Islander, and 2% are reported as other ethnic groups.

Half (51%) of the caregivers under the age of 65 also work outside the home, either in full-time (35%) or part-time (16%) jobs.

Caregiver Well-Being:

Depression is a problem for family caregivers. Over four in ten (44%) CRC family caregivers show clinical symptoms of depression.⁸ Caregivers generally report high stress due to their caregiving situation, irrespective of their care receiver's specific diagnosis. Approximately two-thirds (60%) of caregivers self-report feeling “depressed” or “anxious.” Overall, 59% of caregivers score in the “high burden” range on the Adapted Zarit Interview. And 30% of the caregivers say their physical health is now worse in the last six months.

Caregiver Social Support:

Family caregivers served by CRCs report that they provide an average of 87 hours of care a week to their care receiver, or an average of about *12.4 hours per day*. By comparison, these caregivers receive only 10.2 hours per week (or 1.5 hours per day) of help from family and friends in the care of their relative. Typically, the "informal support" the caregiver receives from his/her own family and friends includes respite, housekeeping, grocery shopping, meals, personal care, and/or managing financial/legal issues.

⁸ As evidenced by scores of 16 or higher on the Center for Epidemiological Studies Depression Scale (CES-D).

Caregiver Service Needs:

The greatest caregiver needs, reported by caregivers at intake, were for general information/orientation (70%), emotional support (63%), and respite care (62%). *Twenty-three percent* of caregivers needed assistance with financial advice and aid, 20% in managing the care receiver's behavioral problems *and* 19% needed legal assistance. (Table 12)

Evaluation Components

The following findings address the requirements of Chapter 1658, as amended, to report on the effectiveness of the CRCs specific to:

1. The costs and amount of each service provided.

CRCs provide a range of services and service options to family caregivers. Services are individually tailored to meet the needs of each caregiver. For many, basic information is enough to meet their immediate needs, while others require further problem-solving, emotional support, or practical help with legal matters or other long-term care concerns.

The top four CRC services⁹ used by family caregivers (in rank order) include: **1) family consultation; 2) follow-up information and referral; 3) in-home respite assistance; and 4) support group** (Figure 1).

The majority of family caregivers using one service only (beyond intake and assessment) increased from 58% in FY 2002-03 to 60% in FY 2003-04. The proportion of family caregivers utilizing two services decreased to 31% from 32% in fiscal year 2002-03, and the proportion of family clients using three or more services stayed at 8% (Figure 2).

During FY 2003-04, **a total of 16,562 family caregivers utilized one or more services** at the eleven CRC sites in California, representing a marginal increase from the previous year (FY 2002-03). Of these, **14,993 (91%) received core CRC services** (i.e., services beyond just information or assessment). The average service use per client across all CRC core services was 24.7 hours during the fiscal year. However, caregivers using CRC respite substantially skewed this average. When respite users are removed, family caregivers received an average of 5.7 hours of service per year (Table 1). **A total of 12,221 family caregivers had active cases¹⁰** during at least some portion of FY 2003-04 (Table 5).

Tables 2 and 3 show the total number of family caregivers receiving CRC services by service type, and the total amount of service used, respectively. Table 4 presents the average amount of service used per family caregiver, by service during FY 2003-04. Table 6 and Figure 3 show voucher service expenditures.

⁹ Excludes those caregivers completing only an intake and/or an assessment or reassessment.

¹⁰ The active caseload total excludes caregivers who receive only intake and/or follow-up information and referral. Caregivers with active cases receive an initial assessment and continue to receive routine reassessments, in addition to other CRC services.

A total of 7,681 family caregivers¹¹ completed the intake process across the eleven CRC sites, a 1% increase from the previous fiscal year. Additionally, during this fiscal period, **6,388 caregivers received an average of .8 hours of follow-up information** during the current fiscal year (Tables 2 and 4).

A total of **4,157 caregivers completed a CRC in-home assessment** to determine their needs for further services, measure their stress and burden, and to develop a care plan. Just over half (55%) of caregivers completing intake went on to be assessed. The number of in-home assessments conducted during FY 2003-04 increased by 4% over the number of assessments conducted during FY 2002-03 (Tables 2 and 5b).

A total of **4,588 family caregivers received a reassessment¹²** conducted at six-month intervals to examine change in caregiver well being over time (Table 2). The number of reassessments performed during this fiscal year increased by 6% over the previous fiscal year.

A total of **11,562 family caregivers received an average of 2.8 hours of family consultation service** each during the fiscal year (Tables 2 and 4). Family consultations offer some combination of information and advice, planning and problem-solving consultation, and/or emotional support and intervention with existing service systems.

A total of **10,899 family caregivers and professionals received family-focused education and training** (Table 10). These typically small group events provide practical information to better enable families to understand cognitive disorders, manage daily care, cope with stress, and plan for long-term care.

A total of 797 caregivers received an average of 9 hours of emotional support and information exchange through attendance at CRC-sponsored support groups. A total of **599 caregivers attended psychoeducational groups**, offered by ten CRCs. Caregivers received an average of 18.3 hours of this service (Tables 2 and 4). These structured sequential class series combine training on practical coping skills, self-care and relaxation techniques.

A total of 227 caregivers received an average of 4.6 hours of **individual counseling** to offer more in-depth emotional support and mental health intervention beyond family consultation. For caregivers who received counseling from subcontracted therapists (e.g., by voucher) the average cost per client was about \$308 for four one-hour sessions (Tables 2, 4, and 6).

A total of 272 caregivers received an average of 1.3 hours of **legal/financial consultation** with a CRC contract attorney as part of the long-term care planning process. The average CRC cost per family client for this service was \$124 (Tables 2, 4, and 6). Regional variations in legal consultation costs at CRCs are shown in Figure 4.

A total of 1,735 family caregivers received CRC **respite assistance**, receiving an average of about 406 hours of respite during the year (Tables 2 and 4). The proportion of family caregivers

¹¹ Another 1,383 service providers and members of the general public also completed a CRC intake during FY 2003-04 (Table 13).

¹² Another 3,422 caregivers received a “status change” in cases where the adult with brain impairment or caregiver had died or the caregiver had moved out of the CRC region (Table 2).

receiving respite services was relatively unchanged this fiscal year, compared to fiscal year 2002-03, due to continued fiscal constraints. Respite services, while delivered to the care receiver, are designed primarily to benefit the family caregiver by relieving the caregiver's constant care responsibilities. Utilization of respite varied from site to site based on caregiver need and the availability of funds and services (Figures 5-8).

2. An assessment of the nature and extent of the demand for services providing caregiver support and an evaluation of their success in meeting this demand.

Chapter 1658, as amended, Section 4362.5(c), defines respite as:

"Substitute care or supervision in support of the caregiver for the purposes of providing relief from the stresses of constant care provision and so as to enable the caregiver to pursue a normal routine and responsibilities. Respite care may be provided in the home or in an out-of-home setting, such as day care centers or short-term placements in inpatient facilities."

Caregivers, who completed the uniform assessment process, reported the need for respite care as slightly greater than the need for emotional help and information (76%, 73% and 71%, respectively). This level of need is related to the strain these families experience:

- *Fifty-nine percent* of caregivers score in the “high burden” range on the Adapted Zarit Interview.
- *Thirty percent* say their physical health is now worse than six months ago.
- **Caregiver depression is high: 44% of caregivers exhibit symptoms of clinical depression.**

The consistently high levels of caregiver burden, fair to poor physical health, and depression suggest that caregivers across the state continue to be a high-risk population. Severe depression may impair the family member's ability to provide continued care for a care receiver. Respite care is greatly needed by caregivers to break from oftentimes 24-hour care demands.

By the end of FY 2003-04, the eleven CRCs provided a total of 283,077 hours of respite care to 1,735 families (Tables 8, Figure 5). About 697 families, on average, received respite services each month at the eleven CRCs (or 63 families per site per month).

- On average, caregivers received eight hours of respite care per week (Table 8).
- Among caregivers using in-home respite, 771 clients used 153,090 hours of “direct pay” in-home respite; while 700 clients used 47,567 hours of vendor in-home respite services.¹³
- Because of the lower cost of "direct pay" in-home respite, **caregivers utilizing the direct-pay option received three times as much service**—(199 hours vs. 68 hours) on

¹³ Some families use more than one type of respite; the sum of totals for individual types of respite exceeds 100 %.

average, per family caregiver (Figure 8).

- The total expenditures for CRC respite care services *including family caregiver share of cost* was \$2,987,275 or \$4,121 per family caregiver per year (Table 9).
- On average, **two thirds (67%) of families who received respite services contributed toward this care through co-payments**, based on family income and household size (Table 9).
- Annual co-payment income collected from families amounted to \$286,296 or 10% of the total cost, thereby reducing the total costs to the State (Table 9).
- **The average monthly cost of CRC respite voucher services per family caregiver was \$344**; \$323 was provided by the CRCs. Family caregivers contributed, on average, a \$21 co-payment (Table 9).

The average cost per family caregiver per month varied from region to region, based on budget allocations for respite, availability of community respite options, and amount of respite care provided per family. As of January 1, 2002, all caregivers new to receiving respite are eligible for a one-year-only \$3,600 respite benefit in order to provide respite to the large number of people on the respite waiting list. A total of 4,756 California family caregivers remained on CRC respite wait lists at the end of the FY 2003-04 (Table 2). Since demand for respite services continues to exceed the resources available at CRCs, family caregivers in need of respite care waited an average of 25 months on a respite waiting list before receiving CRC respite assistance (Table 3).

Throughout the fiscal year, a total of 3,129 cases were closed. **Of cases closed providing a reason, over one-third were closed due to the care receiver's death (38%); in 7% of the cases, the caregiver died or moved. A total of 584 family caregivers reported placing their relative in a residential facility (primarily in a skilled nursing facility) during FY 2003-04** (Table 5, Figures 9 and 10). The number one cited cause for this was "level of care/supervision required" (82% Yes), followed by "physical and emotional strain" at 38% and 35% Yes. Since caregivers are on CRC respite waiting lists for an average of 25 months, invariably some caregivers experience the death or institutionalization of care receivers prior to receiving respite services.

Respite services alone may not meet the multi-faceted needs of family caregivers. At the time of intake, over seven in ten families indicated a need for emotional support. CRCs work to integrate mental health interventions and ongoing contact with family caregivers to ensure a complementary package of supportive services. For the caregivers on respite waiting lists, these other CRC services can help bolster families and help them cope with the burden of care.

3. An analysis of the program in deterring the institutionalization of cognitively impaired adults, allowing caregivers to maintain a normal routine and promoting the continuance of quality care for adults with cognitive impairment.

Caring for a loved one at home with a cognitive impairment/disorder can be extremely difficult

especially when the brain-impaired adult experiences increased confusion, which often leads to paranoia and difficult behaviors. Caregivers may find it hard to care for themselves and maintain personal support systems. Mr. T's and Mr. F's story show the difference caregiver support makes:

Mr. T and his mother came to the US 20 years ago from Russia. His mother started having symptoms of dementia in 1997 when she was just 66 years old. Mr. T was referred to the Bay Area CRC in 2000 by the Alzheimer's Diagnostic Center through UC Davis in Martinez. Mr. T was working full time and his mother could be left alone during the day. She had friends who would visit and also take her on outings. Her favorite activity was hiking. Although he had siblings in the area, Mr. T had to spend every weekend and every evening caring for his mother. Mr. T has taken advantage of the classes offered as well as the Camp for Caring and the Caregiver Retreat. His siblings have begun to give him respite breaks and he now has respite funds from the CRC.

With the help of the family consultant, Mr. T was able to consult with an attorney for long term planning. His mother eventually qualified for Medi-cal and as a result, she was able to receive IHSS (In Home Supportive Services) and attend an Adult Day Health Program five days a week. Mr. T writes thank you notes after each experience, saying "I would like to thank you for the most wonderfully enriching weekend (Caregiver Retreat). It was much more than I expected..." or "Thank you for the respite funding. I couldn't have taken the working vacation job in New York if it hadn't been for FCA. Thanks for your help and always being there." (He had become unemployed and this contract job helped him to meet his expenses) or "Thank you for helping make my birthday weekend an unburdened reality. Respite is great."

Mr. F contacted Southern CRC in November of 2003 after hearing about the center from the Alzheimer's Association. He wanted to get guidance on how to care for his mother who has Alzheimer's Disease. Initially, Mr. F knew very little about his mother's diagnosis and felt lost in his quest to care for her in her own home. He felt the need for information and assistance to be able to care for his mother as he noticed she was becoming increasingly forgetful. He was concerned about how her disease might progress with a resulting increased need for assistance in many areas of functioning. Mr. F lives in a mobile home and his mother lives nearby in her own house and shortly before contacting Southern CRC he was laid off from his job. He wanted and needed to find another job to make ends meet, but felt that he couldn't work and take care of his mother at the same time. He described that he was starting to feel sad more often about his mother's and his circumstances and he felt like the future did not hold any hope for him, just uncertainty and frustration.

During the first meeting, the family consultant provided Mr. F with a brief education about Alzheimer's Disease and some specifics about how to deal with some of his mother's behaviors which were challenging to him such as repeatedly asking what day it is and continually looking for "lost" keys. Mr. F was also provided informational fact sheets about Alzheimer's Disease and other issues faced by people caring for someone with this illness. They also talked about how to go about hiring in-home help and how this type of assistance is paid for. As Mr. F was concerned about the possibility that his mother would need nursing home assistance at some point in the future and because she has very little income or assets, the family consultant also

educated him about MediCal. In addition, due to his mother's low income and need for in-home assistance, Mr. F was provided with information on SSI and IHSS.

In the past year Mr. F has worked hard at finding answers to his many questions and uncertainties and has contacted the CRC several times in regards to his situation. Even though his mother's disease symptoms have worsened to the point that she sometimes doesn't recognize him, Mr. F now feels more certain in his role as caregiver and feels he has more support and a clearer plan in place. He has hired private caregivers to be with his mother during the day and as a result, has started working again. Mr. F spends each night with his mother and is on the respite wait list. He anticipates that this service will help to provide additional in-home support in the near future. Mr. F was encouraged to attend a support group at the Alzheimer's Association and has been going there for the last year. He says that he really values the encouragement and information he gets at this group. Southern CRC provided Mr. F with a legal voucher that he used to discuss estate and MediCal planning issues with an elder law attorney. Mr. F subsequently applied for MediCal on his mother's behalf and was approved. Although he wants to support his mother in her own home for as long as possible, he now feels a sense of security knowing that she would be able to receive nursing home care if needed at some point. Mr. F is also in the process of applying for SSI and IHSS for additional support in the hope that these resources will assist him in continuing to care for his mother in her own home. During our latest reassessment, Mr. F expressed appreciation for the information, support and guidance provided by Southern CRC and indicated that he doesn't think he would have been able to continue to provide the care needed by his mother in her home without this assistance.

CRCs provide emotional and practical support to caregivers, allowing them to better cope with the responsibilities and burdens of caring for their loved one at home. While immediate intervention helps families find alternatives to the institutionalization of a relative, ongoing support is also provided. Throughout the caregiving process, CRC staff members maintain regular contact with families receiving respite care in order to ensure that quality care is being provided. In addition, feedback from caregiver clients is used to improve services and meet the changing needs of family caregivers.

Mr. T's and Mr. F's examples explain why families must be informed about all their options and they must be given support in a time of crisis. Without help, caregivers are at risk of becoming depressed or ill themselves, leaving two people in need instead of one. This risk is even more acute, if the caregiver is elderly. CRC data show that most caregivers contacting CRCs are middle age or older and have modest incomes. Given these demographics, caregivers served by the CRCs are likely to have long-term care needs but limited ability to pay for them. *Without affordable community-based care, many families needing long-term care will resort to Medi-Cal to pay the costs.*

The recent average monthly cost for a Medi-Cal patient in a California skilled nursing facility was \$3,423 — 10 times the \$344 average monthly cost of CRC respite services. Private pay nursing homes cost residents over 13 times (\$4,477 per month) the cost of CRC respite (See Table 7 for Medi-Cal and private pay rate references).

As previously noted, during FY 2003-04, CRCs spent \$2,700,979 providing respite assistance to a total of 1,735 California caregivers. **If each of these family caregivers were forced to place their relative in Medi-Cal nursing homes, the cost would be staggering – over \$71 million**

per year.¹⁴ **Without a doubt, even if CRC respite services help only some portion of family caregivers to deter the institutionalization of the care receiver, the State realizes enormous savings.**

While it may not be appropriate in some cases for family to continue providing care at home, CRC services help many families decide what is best for their family member and themselves. For these families, information and support services help deter the institutionalization of a loved one. It must be noted however, that among the 4,756 families on CRC respite waiting lists, some care receivers will be placed in a nursing home before CRC respite services become available. Unfortunately it is unknown how many of these families might have avoided, or postponed, that painful decision had subsidized respite care been an option.

4. Recommendations for ensuring that unmet needs of cognitively impaired persons and their families are identified and addressed with appropriate programs and services.

In order to better understand the magnitude of needs experienced by adults with cognitive impairment and their families, it is important to first estimate the scope of the problem. An estimated 1.4 million people aged 18 years and older are diagnosed annually with adult onset cognitive disease/disorders (Appendix C, Table 1). Between 12.0 and 18.2 million individuals age 18 and over are currently living with the disease/disorder (Appendix C, Table 2). Even more striking, as many as 11 to 19 percent of the United States and California households may be dealing with the burden of caring for a loved one with an adult onset cognitive disease/disorder (Appendix C, Table 3). Getting the right diagnosis for a loved one with a dementing illness is the first step to reaching appropriate programs and services. Take Mrs. M's caregiving example:

Mrs. M was 67 when she first contacted the Bay Area CRC three years ago about her husband, 76, who had just been diagnosed with dementia. The primary care physician was reluctant to call it Alzheimer's, for fear of scaring the patient. On the recommendation of the CRC family consultant, Mrs. M returned to the doctor and requested a referral to a neurologist, where an official diagnosis was made. Mrs. M tried to do long term planning with her husband's business and family, but since Mr. M was functioning fairly well, no one believed her. With the help of the family consultant, Mrs. M contacted an attorney who helped her get their affairs in order. Mrs. M was referred to the early stage support group for both herself and her husband, classes on caring for someone with dementia (It Takes 2 and Controlling Frustration), as well as how to get a Safe Return bracelet and information on driving and dementia (her husband was still driving).

On going re-assessments have helped Mrs. M when things have changed in her husband's needs. In the past year, the family consultant has met with Mr. M's brother, three of Mr. M's children, as well as Mrs. M to help the family work together in caring for the patient. Mrs. M has been able to hire attendant care so that she gets a break from caregiving and is able to visit her own children and grandchildren. She is also trying to find activities that will enrich her life as she ages, as well as caring for Mr. M. Mrs. M calls when she needs support or needs guidance in dealing with something new in Mr. M's care and says she feels so much better knowing that she is not alone and has someone to talk to when she needs it.

¹⁴ Based on \$41,076 annualized 2002 SNF Medi-Cal rate x 1,735 persons.

The Three Top Needs Identified at Intake (Tables 12 and 13)

- 1) **Seven out of ten (70%) family caregivers and 40% of providers and/or the general public requested basic information** about adult-onset cognitive disorders, a full range of caregiving issues, and the scope of CRC services. Resource information is critical at the time of diagnosis and remains important throughout the duration of the caregiving commitment. Information is needed and requested in the areas of home care and behavior management, emotional support, financial/legal considerations, placement help, and long-term care planning and alternatives.
- 2) **Emotional support was a key need for almost two-thirds (63%) of families.** This indicates a **high demand for services, such as counseling and support groups**, where caregivers can begin to unburden themselves from the enormous stresses of their situations.
- 3) **More than half (62%) of the caregivers indicated a need for respite care services.**

Additionally, direct care for the care receiver, legal information, behavior management advice, legal or financial assistance, and placement help were expressed needs for a significant proportion of families and professionals.

Other Identified Needs

Table 11 presents the top ten unmet needs/service gaps identified by CRCs throughout FY 2003-04 in their respective regions. The most common needs included: a greater availability of respite care services, services for traumatic brain injury survivors, support groups, a range of services in languages other than English affordable SNF and/or residential care, and transportation.

Addressing Identified Service Needs

For CRCs across the state, education and training events continue to be one of the best vehicles for families and professionals to address the high demand for information about cognitive impairments and caregiver support options. For caregivers, the **education events** (Table 10) provide valuable information about care techniques and other low-cost interventions, as well as opportunities to develop greater coping skills. For professionals, educational forums increase public awareness of cognitive impairments, needs of caregivers and interactions between the professional community and local resources. Additionally, the development of new training materials by the CRC system, such as program development in rural communities, and education for special populations, allows CRCs to address the tremendous demand for information, support and assistance for a wide range of caregiving experiences.

The 11 CRCs provided family-focused educational seminars and workshops for 13,789 CRC family clients and professionals. This represents a 14 % decrease in attendance from FY 2002-03.

During FY 2003-04 28,164 participants attended conferences and other educational events held regionally and statewide on issues related to caregiving and adult-onset cognitive impairments. This figure dropped 11% from the previous fiscal year.

Throughout this annual report, we address steps to continue to develop, strengthen and provide CRC caregiver support services. Programs that offer information and emotional support, improve coping and day-to-day behavior management skills, provide access to legal/financial help, and offer respite care, can positively impact caregiver well being and strengthen social supports.

Focus on Link2Care: Merging Support and Technology to Meet Caregiver Needs

The Link2Care (L2C) program, an Internet-based Information and Support resource for family caregivers, continues to experience significant growth. Moving from demonstration project to statewide implementation, caregiver enrollment in Link2Care grew 114% during the last year, up from 700 in 2003 to over 1500 enrolled in 2004. The Link2Care website and discussion group are now available throughout California. Although the program receives frequent inquiries from out-of-state caregivers, Link2Care remains a strictly California-based service.

Our target population is the often isolated and over-burdened caregivers of an individual with dementia who finds it difficult to participate in typical service delivery patterns of face-to-face services within normal business hours due to geographic barriers, full or part-time employment and commitments or overwhelming caregiving demands. Link2Care helps to bridge these barriers by providing support and services in the caregiver's home via the Internet at the caregivers' convenience.

The Link2Care program complements services currently delivered by the CRCs and is meant to provide an enriched information and support environment, which is readily available and convenient to the caregiver 24 hours a day. A caregiver enrolls in the Link2Care program online.

Using a personal user-name and password to enter the secured website, caregivers have access to an information library including fact sheets, articles and selected website links, personal consultation with technical experts in medicine, law and caregiving, a personal journal, moderated discussion group, current caregiver focused news and events and other specialized information services.

Strategic Plan Goals and Achievements

The three-year statewide strategic plan (2001-2003) developed jointly by the CRC Directors DMH, and SRC, to provide a vision for the CRC system in the new millennium was amended and carried-forward into 2003-2004. Below are the identified system goals for the year and highlighted accomplishments.

Goal A. Advocate for using National Family Caregiver Support Program (NFCSP) resources to the maximum benefit for California caregivers.

Objective 1. *Assume leadership role at state and local level to educate families, professionals, and the community about the needs of family caregivers and available resources.*

- Throughout the state, CRC staff members were active in addressing the needs of family caregivers at public forums, resource fairs and Advisory Council Meetings by working in collaboration with AAAs and other community agencies in their respective service areas.
- Some CRC's have also engaged in providing testimony at public forums and expanded outreach scope ads in local papers and radio broadcasts, extending target population services to people over age 60 with chronic illness, and adding new representative members to the Community Advisory Boards.

Objective 2. *Advocate at the state and local level to prevent the fragmentation of services to family caregivers.*

- To address fragmentation, CRC staff assumed a primary role in advocating for a seamless system of caregiver services at community forums, statewide coalition meetings, and in meetings with government officials.
- Some CRC's have participated in various local and regional projects and workgroups designed to meet local needs.

Goal B: Advance the use of technology for the benefit of the CRC System and the caregivers it serves.

Objective 1. *Use Internet technology to disseminate program information and develop more interactive communication across the CRC system.*

- Link2Care, an information and support program, is available as a client service at all CRC locations throughout California. Link2Care grew 143% during the last year, up from 300 in 2002 to over 700 enrolled in 2003 with over 1,700 now in 2004.
- The CRCs continue to expand their websites to links that enhance communication with staff, advisory board, DMH, other CRCs, and long-term care agencies and advocates. Some CRC webpage additions also included more information about community resources, information on issues of concern to caregivers, and tips for coping.

Objective 2. *Develop Internet-based client records system with direct entry and retrieval capability statewide.*

- The CRC system continues in the conversion to a new client record tracking system. The project is scheduled to be completed by the end of the 2004-05 fiscal year.

Objective 3. *Enable staff statewide to utilize the technology (marketing, research, web-based services, etc.)*

- CRCs continued to expand their abilities to use technology in their work with caregivers. Around the state, sites continue to train staff in technology skills, develop more web-based resources, and make software upgrades to increase efficiencies.
- A statewide web site was developed to provide a secure site for staff to access forms, policies, and basic information relevant to their duties within the CRC system.

Objective 4. *Develop strategic partnerships to enhance our use of technology in service delivery. Examples include the following:*

- *Del Oro CRC* maintained bimonthly meetings with Nevada County Long-Term Care Integration Council regarding countywide on-line program to promote referral within senior agencies and reduce fragmentation of services.
- *Southern CRC* collaborates with LHI Counseling and Consultation in web-based support group and counseling options and with the San Diego Union Tribune to provide on-line support services.
- *Orange CRC* participates with South County Seniors to establish “Caregiver Corner” information kiosks with computers, links and featuring [Link2Care](#).
- In anticipation of new computer system. *Del Mar CRC* collaborated with Plantronics to receive a donation of headsets that allow typing while speaking on the phone with clients.

Goal C. Develop a strategy for managing the growth of the CRC system.

Objective 1. *Explore options for managing growth that are both cost-effective and efficient (e.g. establish buying-cooperative for technology products and services.)*

- *Southern CRC* works with the San Diego Association of Non-Profits to develop strategic alliances for service delivery and buying cooperatives.

Objective 2. *Strengthen existing management and administrative infrastructure to support continued growth of the CRC system.*

- The CRCs review their administrative functions and operations on a continuous basis.

Goal D. Build on best practices to expand service options and innovative programs.

Objective 1. *Replicate successful CRC psycho-education groups and best practices in outreach to underserved populations throughout the CRC system.*

- “It Takes Two,” “Powerful Tools,” and “Controlling Frustration” are offered at many of the CRC s. The client response has been positive in both urban and rural settings.
- Fact Sheets have been prepared in Spanish and Chinese.

- *Redwood CRC* has held “It Takes Two” at the Ukiah Indian Health Center and *Mountain CRC* has held the same course in Trinity County as well serving Native American caregivers.

Objective 2. *Research successful national practices to determine the feasibility of replication and implementation throughout the CRC system, including family system models that focus on the caregiver, the care recipient and the extended family.*

- Southern CRC conducted research into a Caregiver-to-Caregiver Network program successfully established in Connecticut.
- The SRC held two two-day meetings for CRC staff to “train the trainers” in CRC-developed programs and courses.

Objective 3. *Expand service options to meet the needs of a growing-and increasingly diverse-population of caregivers.*

- The CRCs are all engaged in various forms of outreach and collaboration in their local areas. The range of these includes *Redwood CRC’s* collaboration with Ukiah Indian Senior Center, *Los Angeles CRC* is teamed with AARP in a project piloted to African Americans and Latinos, *Del Oro CRC* is a member of the Advisory Committee for Chinese Outreach Project: End of Life Medical Decisions, and *Orange CRC* held its 5th Annual Vietnamese Caregivers Respite Day Retreat. *Bay Area CRC* offered “It Takes Two” in Spanish.

Objective 4. *Seek opportunities to secure funding for innovative programs; e.g., one-time only funds.*

- The CRCs have secured one-time-only funds from various AAAs to further their efforts to provide services to caregivers in their areas such as emergency respite and one-time respite needs.

Goal E. Demonstrate CRC program effectiveness through caregiver outcomes.

Objective 1. *Continue to implement the recommendations of the Performance Outcome Task Force.*

- Many of the CRCs utilize various client satisfaction surveys to monitor outcomes and identify areas for improvement.

Objective 2. *Analyze data from assessment/reassessment and service automation and disseminate the findings.*

- *Inland CRC* is implementing a continuous quality improvement program. They have determined outcomes for each service and established ways to collect information to determine if they are meeting these standards.

RECOMMENDATIONS

Based on the findings reported by the CRCs and analyzed by the SRC, the DMH agrees that the following recommendations for identifying and addressing the needs of caregivers should be given consideration.

1. Increase the number of caregivers receiving core CRC services through community-based collaborations and widely disseminated information and education campaigns targeting underserved caregivers, particularly minority and rural caregivers.
2. Promote public policy that advances the consumer-directed model of care for all caregivers and care receivers and supports the prevention, diagnosis, treatment, and cure of brain impairing conditions.
3. Improve assistance to working and isolated caregivers via technology, e.g., increase the number of caregivers using the Link2Care.
4. Explore establishing liaisons with the private sector to provide caregiving resources to caregivers working outside the home.
5. Work cohesively with statewide groups addressing the need for appropriate and affordable long-term care options for care receivers and their family caregivers through public awareness and the development of affordable, accessible, and culturally appropriate long-term care services.
6. Identify viable program options for Traumatic Brain Injury caregivers and their loved ones.
7. Carry out CRC research to: 1) measure and analyze the impact of cognitive disorders on family and caregiver well being, and (2) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers.
8. Enhance local partnerships with AAAs to expand family consultations, counseling, and respite services to caregivers using National Family Caregiver Support Program funds.

TABLE 1
 CAREGIVER RESOURCE CENTERS
 TOTAL CLIENTS SERVED AND
 AVERAGE AMOUNT OF SERVICE PER CLIENT (IN HOURS)
 07/01/2003 through 06/30/2004

| | Total | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|---|--------|-----------------|----------------|-----------------------|---------------|----------------|-----------------|--------------|-----------------|---------------|----------------|---------------|
| Total # of family clients ^a receiving at least one CRC service | 16,562 | 2,801 | 1,337 | 2,790 | 1,282 | 1,681 | 1,490 | 708 | 577 | 1,696 | 802 | 1,398 |
| Total # of family clients ^b receiving CRC core services | 14,993 | 2,701 | 1,261 | 2,719 | 372 | 1,704 | 1,465 | 644 | 545 | 1,648 | 724 | 1,210 |
| Avg. # of hours across ^c CRC core services (excluding respite) | 5.7 | 4.1 | 4.5 | 4.4 | 3.6 | 2.7 | 5.5 | 7.1 | 7.7 | 9.3 | 5.2 | 12.7 |
| Avg. # of hours across ^d CRC core services (including respite) | 24.7 | 16.8 | 23.4 | 27.5 | 53.2 | 12.2 | 19.6 | 29.9 | 36.0 | 24.6 | 44.0 | 32.4 |

a Unduplicated count of client using services. Excludes wait lists.

b Core services include family consultation, follow up I&R, counseling, legal consultation, respite assistance, psychoeducational groups, and support groups.

Excludes intake, assessment/reassessment and wait lists.

c N = 12,582. Based on the number of clients receiving "core" services (N =14,993) minus respite users (N = 1,721).

d N=14,303. Based on the number of clients receiving "core" services, as noted above in "b."

TABLE 2
 CAREGIVER RESOURCE CENTERS
 SERVICES SUMMARY: TOTAL CLIENTS SERVED ^a
 07/01/2003 through 06/30/2004

| Clients Receiving Program Services by Type of Service ^b | Total Clients Served | Average # of Clients Served ^c | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|--|----------------------|--|--------------|-------------|-----------------|------------|-------------|--------------|-----------|--------------|------------|-------------|------------|
| Intake ^d | 7,681 | 698 | 1,357 | 643 | 1,505 | 808 | 590 | 580 | 290 | 202 | 671 | 423 | 612 |
| Follow-up I&R | 6,390 | 639 | 1,351 | 581 | 1,510 | 0 | 601 | 589 | 245 | 217 | 603 | 269 | 424 |
| Assessment | 4,157 | 378 | 655 | 458 | 537 | 269 | 388 | 451 | 145 | 190 | 507 | 154 | 403 |
| Reassessment | | | | | | | | | | | | | |
| Full Reassessment | 4,588 | 417 | 943 | 422 | 522 | 274 | 437 | 405 | 169 | 186 | 756 | 91 | 383 |
| Status Change | 3,819 | 342 | 548 | 293 | 383 | 398 | 397 | 374 | 136 | 221 | 558 | 172 | 339 |
| Family Consultation | 11,562 | 1,051 | 1,889 | 1,053 | 1,789 | 291 | 1,391 | 1,264 | 465 | 512 | 1,429 | 507 | 972 |
| (Avg. number per month) | 2,720 | 247 | 294 | 258 | 320 | 60 | 301 | 357 | 163 | 126 | 476 | 186 | 179 |
| Counseling (Individual) | 227 | 21 | 42 | 41 | 16 | 12 | 11 | 16 | 18 | 18 | 18 | 33 | 2 |
| (Avg. number per month) | 41 | 4 | 4 | 5 | 3 | 3 | 3 | 4 | 4 | 4 | 2 | 7 | 2 |
| Legal/Financial Consult. | 272 | 27 | 37 | 58 | 29 | 3 | 13 | 34 | 27 | 17 | 17 | 37 | 0 |
| Psychoeducational Groups | 599 | 65 | 189 | 112 | 49 | 30 | 22 | 36 | 9 | 11 | 141 | 0 | 0 |
| Link2Care | 1,768 | 161 | 310 | 94 | 226 | 187 | 168 | 329 | 61 | 118 | 81 | 75 | 119 |

a Includes clients served during report period (unduplicated count per type of service).

b Not all CRCs provide all services. Service provision is only reported for clients funded through Chapter 1658 state funds (excludes clients served under special grant programs).

c The statewide average is computed as follows: the number of family clients receiving the service divided by the number of CRC sites providing the service.

d Excludes provider/general community intakes; also does not include written or phone inquiries where an intake was not conducted.

TABLE 2
 CAREGIVER RESOURCE CENTERS
 SERVICES SUMMARY: TOTAL CLIENTS SERVED
 (CONT'D)
 07/01/2003 through 06/30/2004

| Clients Receiving Program Services by Type of Service | Total Clients Served | Average # of Clients Served ^f | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|---|----------------------|--|--------------|-------------|-----------------|------------|-------------|--------------|-----------|--------------|------------|-------------|------------|
| Respite Care | 1,743 | 158 | 184 | 158 | 255 | 68 | 178 | 174 | 75 | 141 | 249 | 179 | 82 |
| Respite: Adult Day Care | 208 | 19 | 9 | 32 | 8 | 10 | 38 | 13 | 7 | 24 | 24 | 33 | 10 |
| Respite: In-home | 1,454 | 132 | 115 | 125 | 223 | 59 | 148 | 161 | 67 | 128 | 204 | 148 | 76 |
| Respite: 24-hour (out of home) | 41 | -- | 25 | 1 | 0 | 5 | 0 | 0 | 0 | 2 | 3 | 4 | 1 |
| Respite: 24-hour (in-home) | 66 | -- | 42 | 6 | 0 | 1 | 2 | 0 | 1 | 3 | 4 | 1 | 6 |
| Respite: Camp | 67 | -- | 67 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Respite: Transport | 14 | -- | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 10 | 1 |
| Respite: Other ^g | 83 | 21 | 0 | 0 | 24 | 1 | 0 | 0 | 0 | 0 | 29 | 29 | 0 |
| Respite (Avg. number per month) | 697 | 63 | 54 | 57 | 96 | 31 | 71 | 64 | 46 | 60 | 87 | 77 | 54 |
| Respite Wait List | 4,910 | 432 | 733 | 459 | 872 | 152 | 589 | 490 | 251 | 209 | 652 | 77 | 426 |
| Caregiver Retreat | 362 | 79 | 46 | 0 | 111 | 0 | 0 | 0 | 0 | 32 | 92 | 0 | 81 |
| Support Groups | 992 | 80 | 48 | 154 | 71 | 54 | 22 | 141 | 99 | 70 | 190 | 84 | 59 |
| (Avg. number per month) | 242 | 23 | 4 | 13 | 21 | 13 | 5 | 44 | 31 | 21 | 48 | 26 | 16 |

^f The statewide average is computed as follows: the number of family clients receiving the service divided by the number of CRC sites providing the service.

^g Includes group respite, provided on an hourly basis.

TABLE 3
 CAREGIVER RESOURCE CENTERS
 DIRECT SERVICE UTILIZATION
 07/01/2003 through 06/30/2004

| Type of Service | Total Units of Service Provided ^a | Average # of Clients Served | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|--------------------------------------|--|-----------------------------|--------------|-------------|-----------------|------------|-------------|--------------|-----------|--------------|------------|-------------|------------|
| Intake ^b | 7,681 clients served | 698 | 1,357 | 643 | 1,505 | 808 | 590 | 580 | 290 | 202 | 671 | 423 | 612 |
| Follow-up I&R ^c | 5,380 hours | 538 | 925 | 568 | 1,053 | 0 | 620 | 483 | 699 | 142 | 436 | 134 | 320 |
| Assessment | 4,173 assess. conducted | 379 | 655 | 458 | 537 | 284 | 389 | 451 | 145 | 190 | 507 | 154 | 403 |
| Reassessment | | | | | | | | | | | | | |
| Full Reassessment | 5,942 | 540 | 1,297 | 535 | 610 | 314 | 526 | 548 | 210 | 233 | 1,107 | 100 | 462 |
| Status Change | 3,909 | 351 | 555 | 293 | 391 | 424 | 397 | 385 | 136 | 229 | 586 | 173 | 340 |
| | reassess. conducted | | | | | | | | | | | | |
| Family Consultation ^c | 31,844 hours | 2,895 | 2,963 | 3,751 | 3,826 | 408 | 2,446 | 4,302 | 2,359 | 1,373 | 5,913 | 1,739 | 2,764 |
| Counseling (Individual) ^c | 1,081 hours | 98 | 160 | 215 | 85 | 78 | 32 | 73 | 114 | 86 | 77 | 158 | 3 |

^a Average units is based on the number of CRC sites providing service.

^b Excludes provider/general community intakes and written or phone inquiries where an intake was not conducted.

^c Unit of service is 15 minutes. Units have been converted to hours for statewide reporting.

TABLE 3
DIRECT SERVICE UTILIZATION (CONT'D)
07/01/2003 through 06/30/2004

| Type of Service | Total Units of Service Provided | Average # of Clients Served | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|--|---------------------------------|-----------------------------|--------------|-------------|-----------------|------------|-------------|--------------|-----------|--------------|------------|-------------|------------|
| Legal/Financial Consultations | 362 hours | 36 | 50 | 58 | 41 | 3 | 14 | 34 | 37 | 17 | 17 | 91 | 0 |
| Psychoeducational Groups ^d | 10,835 hours | 1,187 | 6,882 | 1,117 | 573 | 97 | 240 | 396 | 126 | 102 | 1,302 | 0 | 0 |
| Total Respite ^e | 281,311 hours | 25,734 | 34,172 | 23,819 | 61,072 | 18,490 | 15,627 | 20,561 | 14,678 | 15,477 | 25,269 | 28,260 | 23,886 |
| Respite: Adult Day Care ^f | 7,655 days | 726 | 765 | 1,049 | 339 | 540 | 859 | 592 | 218 | 778 | 572 | 1,468 | 475 |
| Respite: In-home | 201,149 hours | 18,242 | 18,353 | 13,836 | 58,268 | 13,486 | 9,374 | 16,417 | 12,480 | 9,783 | 17,481 | 15,526 | 16,145 |
| Respite: 24-hour ^g (out of home) | 294 24 hr days | -- | 166 | 12 | 0 | 45 | 0 | 0 | 0 | 6 | 17 | 46 | 2 |
| Respite: 24-hour (in home) | 627 24 hr days | -- | 270 | 98 | 0 | 5 | 10 | 0 | 28 | 4 | 12 | 18 | 182 |
| Respite: Camp ^d | 134 24 hr days | -- | 134 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Respite: Transportation | 1,362 1-way trip | -- | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 187 | 879 | 296 |
| Respite: Other ^f | 4,458 hours | -- | 0 | 0 | 432 | 16 | 0 | 0 | 0 | 0 | 3,088 | 922 | 0 |
| Avg. # Months on Respite Wait List | N/A | 25 | 20 | 14 | 13 | 72 | 18 | 8 | 26 | 12 | 15 | 5 | 15 |
| Caregiver Retreat ^d | 1,368 24 hr days | 318 | 96 | 0 | 222 | 0 | 0 | 0 | 0 | 196 | 300 | 0 | 554 |
| Support Groups ^d | 8,346 hours | 714 | 84 | 1,138 | 1,082 | 273 | 121 | 1,591 | 828 | 588 | 1,173 | 1,114 | 354 |

^d Total hours reflect the sum of hours received by each participant at a group event

^e All respite figures have been converted to hours to obtain total respite hours.

^f Assumes an average of seven hours per day.

^g Includes overnight and weekend respite care at hospitals and residential facilities.

TABLE 4
CAREGIVER RESOURCE CENTERS
AMOUNT OF CRC SERVICE PER CLIENT (in hours)

07/01/2003 through 06/30/2004

| CRC Service Type | Average Hours ^a | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|---------------------------|----------------------------|--------------|-------------|-----------------|------------|-------------|--------------|-----------|--------------|------------|-------------|------------|
| Follow-Up I&R | 0.8 | 0.7 | 1.0 | 0.7 | 0.0 | 1.0 | 0.8 | 2.9 | 0.7 | 0.7 | 0.5 | 0.8 |
| Family Consultation | 2.8 | 1.6 | 3.6 | 2.1 | 1.4 | 1.8 | 3.4 | 5.1 | 2.7 | 4.1 | 3.4 | 2.8 |
| Counseling (Individual) | 4.6 | 3.8 | 5.0 | 5.3 | 4.6 | 2.9 | 4.6 | 6.3 | 4.8 | 4.3 | 4.8 | 1.5 |
| Legal/Financial Consult | 1.3 | 1.4 | 1.0 | 1.4 | 1.0 | 1.1 | 1.0 | 1.4 | 1.0 | 1.0 | 2.5 | 0.0 |
| Psychoeducational Groups | 18.3 | 36.4 | 10.0 | 11.0 | 3.2 | 14.1 | 11.0 | 14.0 | 9.3 | 9.2 | 0.0 | 0.0 |
| Respite Care ^b | 70.7 | 145.2 | 120.6 | 35.0 | 113.8 | 38.8 | 83.5 | 93.0 | 39.8 | 52.7 | 48.3 | 91.7 |
| Support Groups | 9.0 | 0.0 | 2.9 | 15.2 | 5.1 | 5.5 | 11.3 | 8.4 | 8.4 | 6.2 | 13.3 | 6.0 |

a Based on the total number of units (hours) utilized per service divided by the total number of family clients receiving the service during the report period.

b For respite care, the calculation is based on the total number of respite hours divided by the respite average monthly caseload. The total amount of respite care per family client breaks down into 23.5 hours per month or 5.4 hours per week.

TABLE 5
 CAREGIVER RESOURCE CENTERS
 CASE STATUS SUMMARY
 07/01/2003 through 06/30/2004

| | Total | Bay Area CRC | Redwood | Los Angeles | Inland | Del Oro | Southern | Coast | Mountain | Valley | Del Mar | Orange |
|---|--------|-----------------|---------|----------------|--------|---------|----------|-------|----------|--------|---------|--------|
| Total Active Cases at Start of Report Period | 7,916 | 1,244 | 621 | 1,334 | 482 | 928 | 830 | 298 | 375 | 890 | 311 | 603 |
| # New Clients Added | 4,239 | 679 | 459 | 547 | 296 | 381 | 471 | 145 | 190 | 508 | 156 | 407 |
| # Client Reactivated ^a | 66 | 10 | 1 | 8 | 0 | 2 | 28 | 0 | 4 | 3 | 3 | 7 |
| Total Active Cases During Report Period ^b | 12,221 | 1,933 | 1,081 | 1,889 | 778 | 1,311 | 1,329 | 443 | 569 | 1,401 | 470 | 1,017 |
| # Cases Made Inactive | 42 | 0 | 0 | 0 | 41 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| # Active Cases Closed | 3,329 | 484 | 285 | 365 | 277 | 227 | 359 | 135 | 208 | 524 | 156 | 309 |
| # Inactive Cases Closed | 152 | 58 | 7 | 15 | 5 | 0 | 11 | 1 | 0 | 13 | 12 | 30 |
| Reason closed | | | | | | | | | | | | |
| --Caregiver died | 55 | 0 | 6 | 9 | 1 | 7 | 10 | 2 | 3 | 12 | 4 | 1 |
| --Caregiver moved | 189 | 30 | 24 | 30 | 1 | 6 | 19 | 15 | 19 | 22 | 10 | 13 |
| --Patient died | 1,347 | 214 | 131 | 185 | 15 | 151 | 125 | 63 | 73 | 189 | 52 | 149 |
| --Other ^c | 829 | 235 | 59 | 160 | 7 | 63 | 70 | 3 | 0 | 163 | 42 | 27 |
| # Patients placed in facilities | 630 | 61 | 48 | 43 | 5 | 65 | 64 | 81 | 88 | 127 | 11 | 37 |
| --SNF | 425 | 40 | 33 | 27 | 3 | 35 | 36 | 55 | 56 | 103 | 10 | 14 |
| --Rehab | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 |
| --Acute Hospital | 4 | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 2 | 0 | 0 |
| --Board & Care | 184 | 20 | 14 | 14 | 1 | 22 | 26 | 23 | 25 | 16 | 1 | 22 |
| --Other | 28 | 1 | 1 | 1 | 1 | 8 | 1 | 3 | 6 | 6 | 0 | 0 |
| Total Active Cases at End of Report Period ^d | 8,850 | 1,449 | 796 | 1,524 | 460 | 1,084 | 970 | 308 | 361 | 877 | 313 | 708 |

a Cases previously closed or inactive made active by providing new CRC services.

b Includes clients who have been assessed and are on the CRC respite wait list only or clients not currently using CRC services.

c Includes caregivers who become ineligible or decline further services, or who cannot be reached for reassessment.

d Subtracts cases made inactive and active cases closed from the Total Active Cases during the fiscal year.

e Del Oro CRC has encountered Y2K-related data problems. A new preliminary report put the year-end number at 1,284 vs. 4,302 in SA.

TABLE 5b
CAREGIVER RESOURCE CENTERS ^{abc}
CAREGIVER ASSESSMENT RETURN RATES/CES-D SCORE
07/01/2003 through 06/30/2004

| CRC | July – September 2003 | | | | October – December 2003 | | | | January – March 2004 | | | | April – June 2004 | | | | TOTAL | | | |
|--------------|-----------------------|---------------------------|------------|------------------|-------------------------|---------------------------|------------|------------------|----------------------|---------------------------|------------|------------------|-------------------|---------------------------|------------|------------------|------------------|---------------------------|------------|------------------|
| | Total Assessed # | Questionnaires Returned # | % | Avg. CES-D Score | Total Assessed # | Questionnaires Returned # | % | Avg. CES-D Score | Total Assessed # | Questionnaires Returned # | % | Avg. CES-D Score | Total Assessed # | Questionnaires Returned # | % | Avg. CES-D Score | Total Assessed # | Questionnaires Returned # | % | Avg. CES-D Score |
| Bay Area | 175 | 107 | 61% | 20 | 159 | 42 | 26% | 17 | 181 | 76 | 42% | 20 | 140 | 58 | 41% | 18 | 655 | 283 | 43% | 19 |
| Redwood | 91 | 78 | 85% | 18 | 100 | 83 | 83% | 18 | 150 | 126 | 84% | 16 | 117 | 88 | 75% | 19 | 458 | 375 | 82% | 18 |
| Los Angeles | 154 | 143 | 92% | 15 | 132 | 109 | 82% | 16 | 129 | 122 | 94% | 15 | 122 | 119 | 97% | 17 | 537 | 493 | 92% | 16 |
| Inland | 59 | 50 | 85% | 18 | 68 | 53 | 78% | 18 | 84 | 70 | 83% | 18 | 58 | 41 | 71% | 18 | 269 | 214 | 80% | 18 |
| Del Oro | 131 | 128 | 97% | 12 | 80 | 74 | 92% | 10 | 110 | 101 | 91% | 11 | 68 | 63 | 92% | 13 | 389 | 366 | 94% | 11 |
| Southern | 141 | 132 | 93% | 17 | 97 | 84 | 86% | 15 | 108 | 100 | 92% | 17 | 105 | 92 | 87% | 15 | 451 | 408 | 90% | 16 |
| Coast | 50 | 50 | 100% | 16 | 37 | 37 | 100% | 18 | 25 | 25 | 100% | 18 | 33 | 33 | 100% | 18 | 145 | 145 | 100% | 17 |
| Mountain | 45 | 44 | 97% | 18 | 34 | 33 | 97% | 16 | 63 | 60 | 95% | 15 | 48 | 46 | 95% | 17 | 190 | 183 | 96% | 16 |
| Valley | 147 | 145 | 98% | 15 | 109 | 109 | 100% | 15 | 139 | 139 | 100% | 14 | 112 | 112 | 100% | 16 | 507 | 505 | 100% | 15 |
| Del Mar | 39 | 32 | 82% | 15 | 36 | 31 | 86% | 17 | 40 | 38 | 95% | 15 | 39 | 35 | 89% | 19 | 154 | 136 | 88% | 16 |
| Orange | 107 | 105 | 98% | 18 | 125 | 119 | 95% | 19 | 93 | 88 | 94% | 18 | 78 | 70 | 89% | 16 | 403 | 382 | 95% | 18 |
| Total | 1,139 | 1,014 | 89% | 16 | 977 | 774 | 79% | 16 | 1,122 | 945 | 84% | 16 | 920 | 757 | 82% | 17 | 4,158 | 3,546 | 85% | 16 |

a Includes questionnaires returned by the end of the reporting period.

b The mail-back questionnaire was limited only to items related to the CES-D (depression) score.

c A score of 16 or higher on the CES-D indicates the presence of symptoms of clinical depression.

TABLE 6
CAREGIVER RESOURCE CENTERS
EXPENDITURES FOR VOUCHER SERVICES
07/01/2003 through 06/30/2004

| Expenditures ^a | Total \$ | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|---|--------------------|------------------|------------------|-----------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|
| In Home Respite ^b | \$2,261,106 | \$157,395 | \$170,487 | \$571,315 | \$135,256 | \$159,087 | \$202,767 | \$145,407 | \$144,996 | \$193,664 | \$225,654 | \$155,078 |
| (Avg. \$ per family client) | \$1,555 | \$1,369 | \$1,364 | \$2,597 | \$2,292 | \$1,075 | \$1,259 | \$2,170 | \$1,132 | \$949 | \$1,525 | \$2,041 |
| Adult Day Care Respite ^b | 275,741 | 22,478 | 43,979 | 14,450 | 16,101 | 40,374 | 13,382 | 9,810 | 20,167 | 15,450 | 56,941 | 22,609 |
| (Avg. \$ per family client) | 1,326 | 2,498 | 1,374 | 1,806 | 1,610 | 1,062 | 1,029 | 1,401 | 840 | 644 | 1,725 | 2,261 |
| 24-hour In-Home Respite ^b | 57,337 | 25,187 | 6,553 | 0 | 875 | 2,260 | 0 | 2,940 | 1,615 | 1,047 | 2,160 | 14,700 |
| (Avg. \$ per family client) | 869 | 600 | 1,092 | 0 | 875 | 1,130 | 0 | 2,940 | 538 | 262 | 2,160 | 2,450 |
| 24-hour Out-of-Home Respite ^b | 38,478 | 23,490 | 1,620 | 0 | 4,614 | 0 | 0 | 0 | 555 | 2,499 | 5,400 | 300 |
| (Avg. \$ per family client) | 938 | 940 | 1,620 | 0 | 923 | 0 | 0 | 0 | 278 | 833 | 1,350 | 300 |
| Respite Camp | 41,110 | 41,110 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| (Avg. \$ per family client) | 614 | 614 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Other Respite ^b | 28,012 | 0 | 0 | 4,301 | 272 | 0 | 0 | 0 | 0 | 9,784 | 13,655 | 0 |
| (Avg. \$ per family client) | 337 | 0 | 0 | 187 | 272 | 0 | 0 | 0 | 0 | 337 | 471 | 0 |
| Legal Consultation | 33,295 | 4,820 | 4,025 | 6,180 | 300 | 1,031 | 3,910 | 3,650 | 1,450 | 1,275 | 6,654 | 0 |
| (Avg. \$ per family client) | 122 | 130 | 69 | 213 | 100 | 79 | 115 | 135 | 85 | 75 | 180 | 0 |
| Counseling (Individual) ^c | 50,745 | 10,550 | 10,860 | 0 | 1,530 | 850 | 0 | 7,565 | 4,655 | 4,920 | 9,815 | 0 |
| (Avg. \$ per family client) | 224 | 251 | 302 | 0 | 128 | 170 | 0 | 504 | 258 | 273 | 297 | 0 |
| Total | \$2,785,824 | \$285,030 | \$237,524 | \$596,246 | \$158,948 | \$203,602 | \$220,059 | \$169,372 | \$173,438 | \$228,639 | \$320,279 | \$192,687 |

a These figures include only funds expended under Chapter 1658 contracts; special grants are excluded. However, respite expenditures also include some funds collected from client co-payments, used to extend CRC respite budgets. Expenditures reflect voucher costs only; salaried CRC staff time is excluded.

b Average respite expenditures are based on the total number of family clients receiving each type of respite (includes short-term and one-time-only respite clients). See also Table 8.

c Reflects 227 clients receiving vouchered (subcontracted) counseling only. Individual sites vary as to whether counseling services are provided by CRC staff or by subcontract.

TABLE 7
 CAREGIVER RESOURCE CENTERS
 COMPARISON OF CRC RESPITE VOUCHER COSTS
 AND SKILLED NURSING FACILITY (SNF) COSTS
 07/01/2003 THROUGH 06/30/2004

| Service | Average Cost per Client per Month | Average Cost per Client per Year |
|--|--------------------------------------|-------------------------------------|
| CRC Respite (Voucher) | \$137 ^a | \$1,649 |
| Skilled Nursing Facility: Medi-Cal | \$3,423 ^b | \$41,076 |
| Skilled Nursing Facility: Private Pay | \$4,477 ^c | \$53,724 |

a Based on total expenditures and family client caseload figures for CRC respite voucher services for FY 2003-2004 (See table 9). Includes an average co-payment of \$21.

b Source: California Department of Health Services, Medi-Cal Policy Division, Rate Development Branch, Long-Term Care Reimbursement Unit. (Note: Based on weighted average of \$113.73 per day, effective 8/1/2002.)

c Source: This 2004 estimate was reported by California Advocates for Nursing Home Reform (CANHR), http://www.canhr.org/medcal/EPRrates_2004.html.

TABLE 8
 CAREGIVER RESOURCE CENTERS
 HOURS OF RESPITE CARE PROVIDED
 07/01/2003 through 06/30/2004

| Respite | Total | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|---|---------|-----------------|----------------|-----------------------|---------------|----------------|-----------------|--------------|-----------------|---------------|----------------|---------------|
| Total Number of Family Clients Served | 1,743 | 184 | 158 | 255 | 68 | 178 | 174 | 75 | 141 | 249 | 179 | 82 |
| Average Monthly Respite Caseload ^a | 697 | 54 | 57 | 96 | 31 | 71 | 64 | 46 | 60 | 87 | 77 | 54 |
| Total Hours of Respite ^b | 281,311 | 34,172 | 23,819 | 61,072 | 18,490 | 15,627 | 20,561 | 14,678 | 15,477 | 25,269 | 28,260 | 23,886 |
| Average Number of Hours of Respite per Family Client | 402 | 633 | 418 | 636 | 596 | 220 | 321 | 319 | 258 | 290 | 367 | 442 |
| Average Number of Hours of Respite per Family Client per Month ^c | 34 | 53 | 35 | 53 | 50 | 18 | 27 | 27 | 22 | 24 | 31 | 37 |
| Average Number of Hours of Respite per Family Client per Week ^d | 8 | 12 | 8 | 12 | 12 | 4 | 6 | 6 | 5 | 6 | 7 | 9 |

a Figure represents the total monthly caseload at all 11 CRCs statewide; the average monthly caseload across CRCs is 63 family clients receiving respite per month per CRC site.

b Out-of-home respite for day care was calculated at an average of 7 hours per day. Excludes respite transportation assistance.

c Average Number of Hours of Respite per Family Client were computed based on 12 months of service provision.

d Calculated using 4.3 weeks per month.

**TABLE 9
CAREGIVER RESOURCE CENTERS
EXPENDITURES FOR RESPITE VOUCHER SERVICES
07/01/2003 through 06/30/2004**

| Respite | Total | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|---|-------------|-----------------|----------------|--------------------|---------------|----------------|-----------------|--------------|-----------------|---------------|----------------|---------------|
| Total Cost of Respite Services ^a | \$2,998,298 | \$293,635 | \$260,410 | \$ 632,443 | \$170,435 | \$227,322 | \$233,458 | \$187,647 | \$200,203 | \$249,372 | \$343,989 | \$199,384 |
| Total Contribution by Family clients ^b | 286,969 | 23,975 | 37,771 | 33,141 | 13,170 | 25,601 | 17,308 | 29,490 | 32,710 | 26,927 | 40,179 | 6,697 |
| Total CRC Respite Expenditure ^c | \$2,711,328 | \$269,660 | \$222,639 | \$599,302 | \$157,265 | \$201,721 | \$216,150 | \$158,157 | \$167,492 | \$222,445 | \$303,810 | \$192,687 |
| Total No. of Family Clients | 1,743 | 184 | 158 | 255 | 68 | 178 | 174 | 75 | 141 | 249 | 179 | 82 |
| Total No. of Family Clients Contributing Co-payment ^d | 1,162 | 106 | 119 | 178 | 62 | 117 | 122 | 74 | 97 | 159 | 95 | 33 |
| Total Respite Clients | 1,933 | 258 | 164 | 255 | 76 | 188 | 174 | 75 | 157 | 267 | 225 | 94 |
| Percent of Families Contributing a Co-payment | 67% | 58% | 75% | 70% | 91% | 66% | 70% | 99% | 69% | 64% | 53% | 40% |
| Average Annual CRC Costs per Family Client ^e | \$1,403 | \$1,045 | \$1,358 | \$2,350 | \$2,069 | \$1,073 | \$1,242 | \$2,109 | \$1,067 | \$833 | \$1,350 | \$2,050 |
| Average Annual Reimbursement (co-payment) per Family Client | \$246 | \$226 | \$317 | \$186 | \$212 | \$219 | \$142 | \$399 | \$337 | \$169 | \$423 | \$203 |
| Average Annual Cost per Family client | \$1,649 | \$1,271 | \$1,675 | \$2,536 | \$2,281 | \$1,292 | \$1,384 | \$2,508 | \$1,404 | \$1,022 | \$1,773 | \$2,253 |
| Average CRC Cost per Family Client per Month | \$117 | \$87 | \$113 | \$196 | \$172 | \$89 | \$104 | \$176 | \$89 | \$69 | \$113 | \$171 |
| Average Reimbursement (co- payment) per Family Client per Month | \$21 | \$19 | \$26 | \$16 | \$18 | \$18 | \$12 | \$33 | \$28 | \$14 | \$35 | \$17 |
| Average Cost per Family Client per Month | \$137 | \$106 | \$140 | \$211 | \$190 | \$108 | \$115 | \$209 | \$117 | \$84 | \$148 | \$188 |

a Excludes costs of staff time for arranging and monitoring respite services and for administrative costs.

b This is the share of cost for families using "direct pay" respite.

c Total CRC respite expenditure.

d CRCs provide some emergency and short-term respite where families do not pay a co-payment.

e Calculated based on the average respite caseload per month.

TABLE 10
 CAREGIVER RESOURCE CENTERS
 EDUCATION AND TRAINING ACTIVITIES
 07/01/2003 through 06/30/2004

| Education/Training Activity Type | Total CRCs ^a | Bay Area CRC | Redwood CRC | Los Angeles CRC | Inland CRC | Del Oro CRC | Southern CRC | Coast CRC | Mountain CRC | Valley CRC | Del Mar CRC | Orange CRC |
|--------------------------------------|-------------------------|--------------|-------------|-----------------|------------|-------------|--------------|-----------|--------------|------------|-------------|------------|
| FAMILY-FOCUSED EDUCATION/TRAINING | | | | | | | | | | | | |
| 1. Total number of persons attending | 13,795 | 1,846 | 960 | 1,282 | 223 | 3,090 | 3,753 | 155 | 328 | 1,523 | 288 | 347 |
| OTHER EDUCATION/TRAINING EVENTS | | | | | | | | | | | | |
| 2. Total number of persons attending | 4,428 | 373 | 946 | 721 | 0 | 313 | 910 | 7 | 53 | 754 | 351 | 0 |
| ORIENTATION TO CRC SERVICES | | | | | | | | | | | | |
| 3. Total number of persons attending | 9,947 | 546 | 933 | 1,912 | 0 | 1,088 | 441 | 15 | 74 | 3,744 | 1,121 | 73 |
| Total | 28,170 | 2,765 | 2,839 | 3,915 | 223 | 4,491 | 5,104 | 177 | 455 | 6,021 | 1,760 | 420 |

a Duplicated Count

TABLE 11
 CAREGIVER RESOURCE CENTERS
 TOP TEN UNMET NEEDS/SERVICE GAPS IDENTIFIED
 BY CRCS IN THEIR SERVICE REGIONS
 07/01/2003 through 06/30/2004

| NEEDS IDENTIFIED | # OF CRCS REPORTING |
|---|----------------------------|
| Respite Services | 6 |
| TBI Services and Resources | 4 |
| Support Group | 4 |
| Bilingual Services | 4 |
| SNF/Residential Care (affordable) | 3 |
| Transportation | 3 |
| Case Management Services | 2 |
| Adult Day Care | 2 |
| Services for Caregivers of Young Adults | 2 |
| Counseling/Neuropsychological Services | 2 |

TABLE 12
 CAREGIVER RESOURCE CENTERS
 MAJOR NEEDS/INFORMATION REQUESTED BY
 FAMILIES/CAREGIVERS AT CRC INTAKE ^a
 07/01/2003 through 06/30/2004

| NEEDS IDENTIFIED | # REPORTING | % REPORTING ^b | RANK |
|---|-------------|--------------------------|------|
| General Information/Orientation to Brain Impairments | 5,302 | 70.4% | 1 |
| Emotional Support | 4,746 | 63.1% | 2 |
| Respite Care (for the caregiver) ^c | 4,630 | 61.5% | 3 |
| Direct Care of the Adult With Brain Impairment ^d | 2,265 | 30.1% | 4 |
| Financial Advice/Aid | 1,702 | 22.6% | 5 |
| Behavior Management Advice | 1,501 | 19.9% | 6 |
| Legal Information/Advice | 1,463 | 19.4% | 7 |
| Other | 1,334 | 17.7% | 8 |
| Placement Help | 655 | 8.7% | 9 |
| Diagnostic/Medical Advice | 495 | 6.6% | 10 |
| Rehabilitation | 94 | 1.2% | 11 |
| Public Policy/Research | 18 | 0.2% | 12 |

a Needs identified are based on responses from 7,527 families/caregivers at intake.

b Percentages exceed 100% due to multiple problems/needs.

c Respite care refers to expressions of wanting “a break” from caregiving and questions about CRC respite programs or other community resources which provide respite care.

d Direct care of brain-impaired adults refers to questions about hiring home help, arranging care services for long-distance caregivers, equipment needs, medical supplies, home safety, basic care strategies (e.g. lifting), etc.

TABLE 13
 CAREGIVER RESOURCE CENTERS
 MAJOR NEEDS/INFORMATION REQUESTED BY
 PROVIDERS/GENERAL PUBLIC AT CRC INTAKE ^a
 07/01/2003 through 06/30/2004

| NEEDS IDENTIFIED | # REPORTING | % REPORTING ^b | RANK |
|--|--------------------|---------------------------------|-------------|
| General Information/Orientation to Brain Impairments | 559 | 40.4% | 1 |
| Other | 179 | 12.9% | 2 |
| Respite Care (for the caregiver) | 151 | 10.9% | 3 |
| Legal Information/Advice | 138 | 10.0% | 4 |
| Emotional Support | 84 | 6.1% | 5 |
| Direct Care of the Adult with Brain Impairment | 51 | 3.7% | 6 |
| Placement Help | 31 | 2.2% | 7 |
| Financial Advice/Aid | 24 | 1.7% | 8 |
| Training | 22 | 1.6% | 9 |
| Behavior Management Advice | 20 | 1.4% | 10 |
| Diagnostic/Medical advice | 14 | 1.0% | 11 |
| Rehabilitation | 6 | 0.4% | 12 |
| Public Policy/Research | 0 | 0% | 13 |

a Needs identified are based on responses from 1,383 providers/general public callers at intake.

b Percentages exceed 100% due to multiple problems/needs.

c Respite care refers to expressions of wanting “a break” from caregiving and questions about CRC respite programs or other community resources which provide respite care.

d Direct care of brain-impaired adults refers to questions about hiring home help, arranging care services for long-distance caregivers, equipment needs, medical supplies, home safety, basic care strategies (e.g. lifting), etc.

FIGURE 1
CAREGIVER RESOURCE CENTERS
TOP FOUR SERVICES AND NUMBER OF CLIENTS SERVED
FY 2003-2004

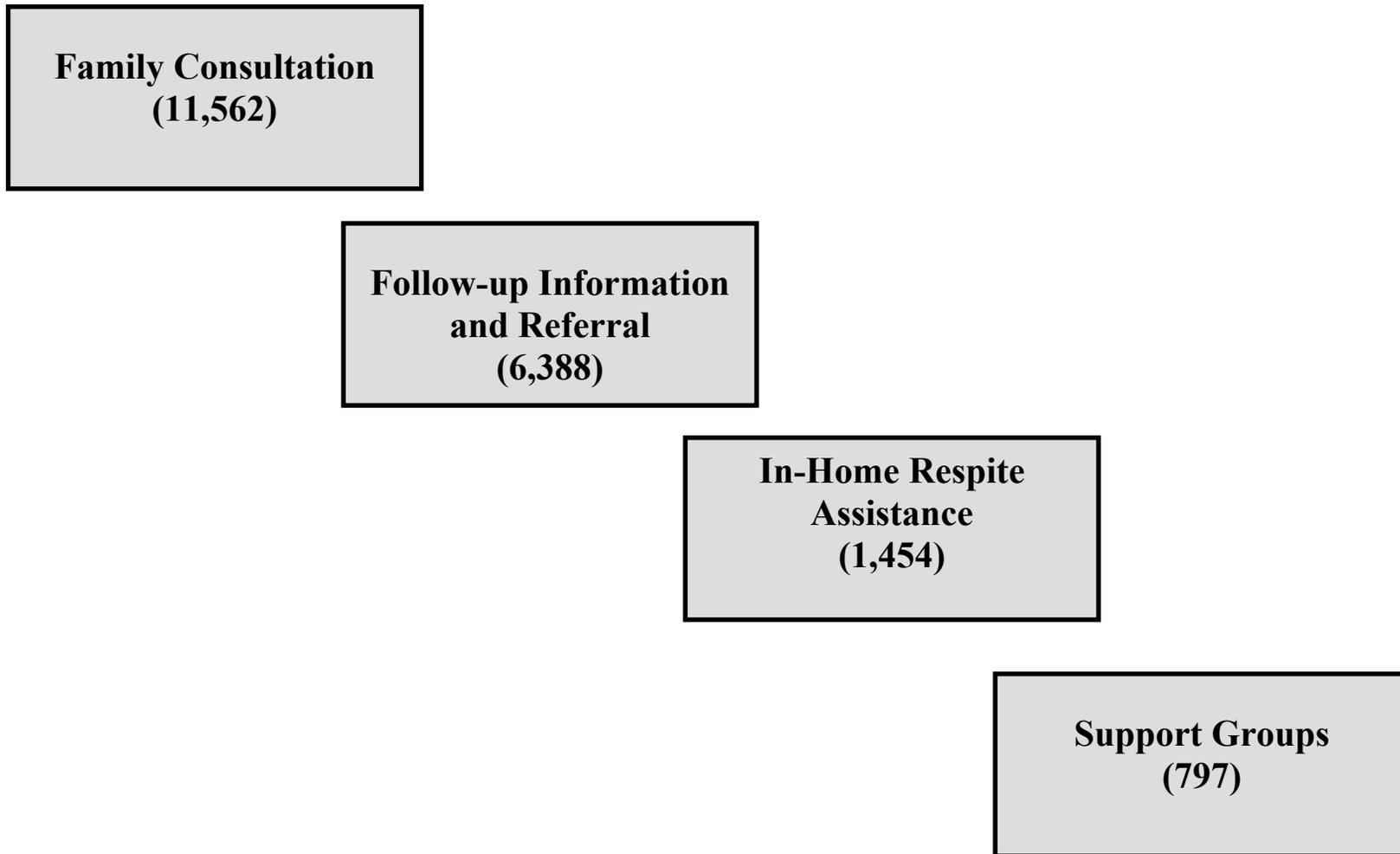
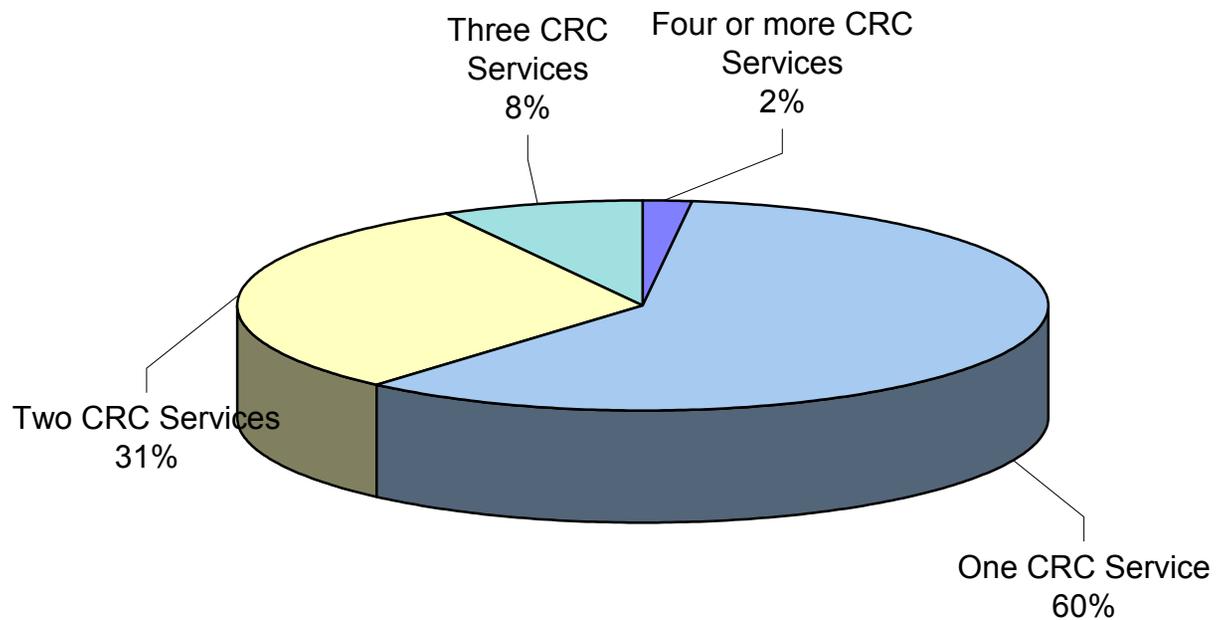


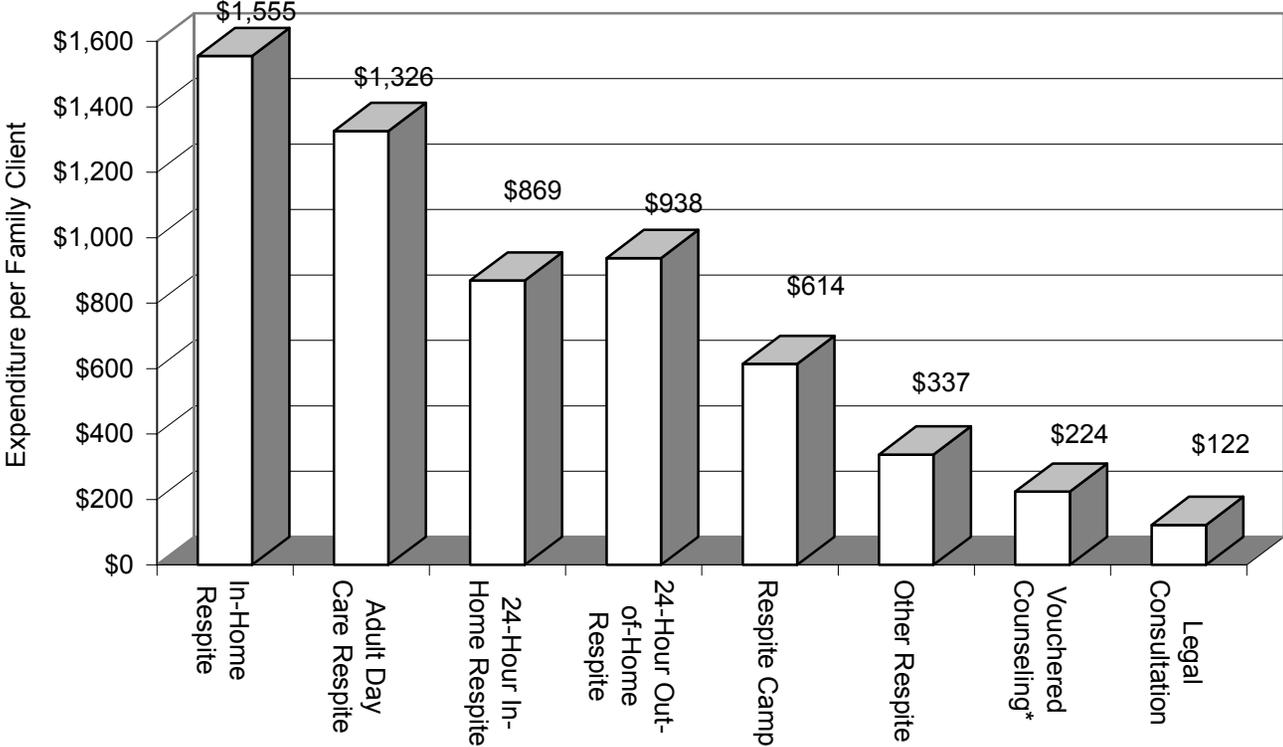
FIGURE 2
CAREGIVER RESOURCE CENTERS
THE PROPORTION OF FAMILY CAREGIVERS RECEIVING ONE,
TWO, THREE, OR FOUR PLUS SERVICES ^a
FY 2003-2004



N = 15,687

^a Includes CRC “core” services only (family consultation, follow-up information, counseling, psychoeducational groups, support groups, family-focused education, legal consultation, and respite). Access services are excluded (intake, assessment, and reassessment).

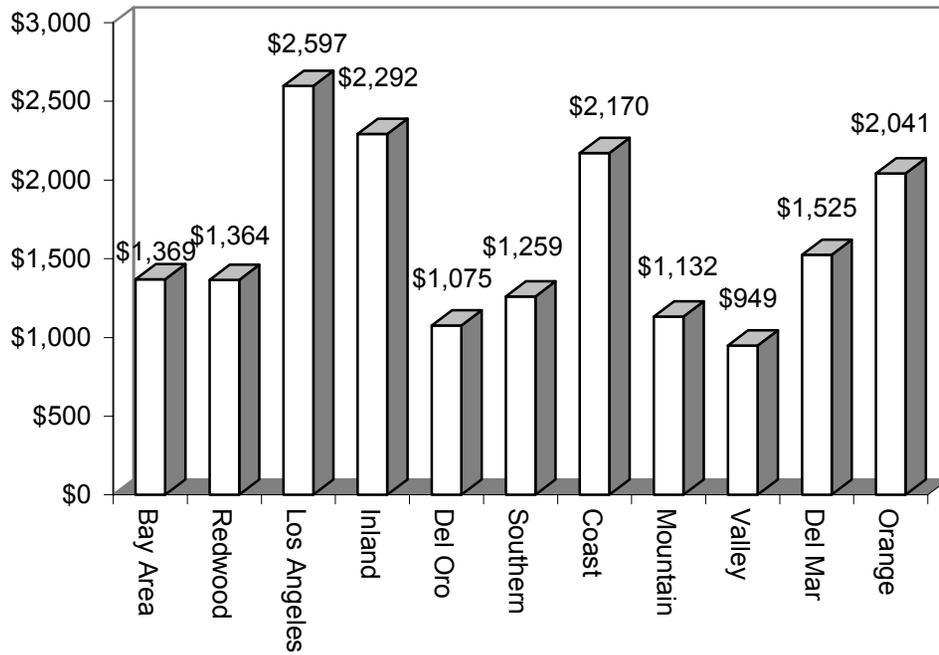
**FIGURE 3
 CAREGIVER RESOURCE CENTERS
 AVERAGE COST PER YEAR PER FAMILY CLIENT FOR
 CRC VOUCHER SERVICES, FY 2003-2004**



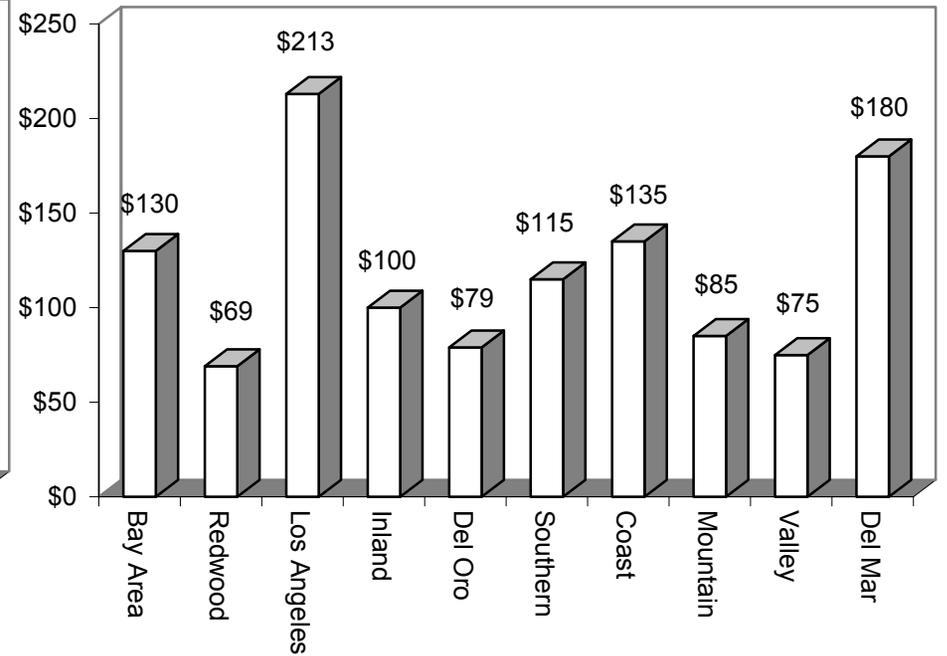
*Excludes counseling provided by salaried CRC staff.

FIGURE 4
CAREGIVER RESOURCE CENTERS
ANNUAL COST PER FAMILY CLIENT BY CRC SITE:
IN-HOME RESPITE AND LEGAL CONSULTATIONS
FY 2003-2004

In-Home Respite



Legal Consultations*



* Orange CRC offers pro bono legal services and free group legal workshops as part of their family-focused education and training services.

FIGURE 5
 CAREGIVER RESOURCE CENTERS
 RESPITE CARE BY CRC SITE – TOTAL NUMBER OF FAMILY CLIENTS
 SERVED IN FY 2002-2003 AND FY 2003-2004

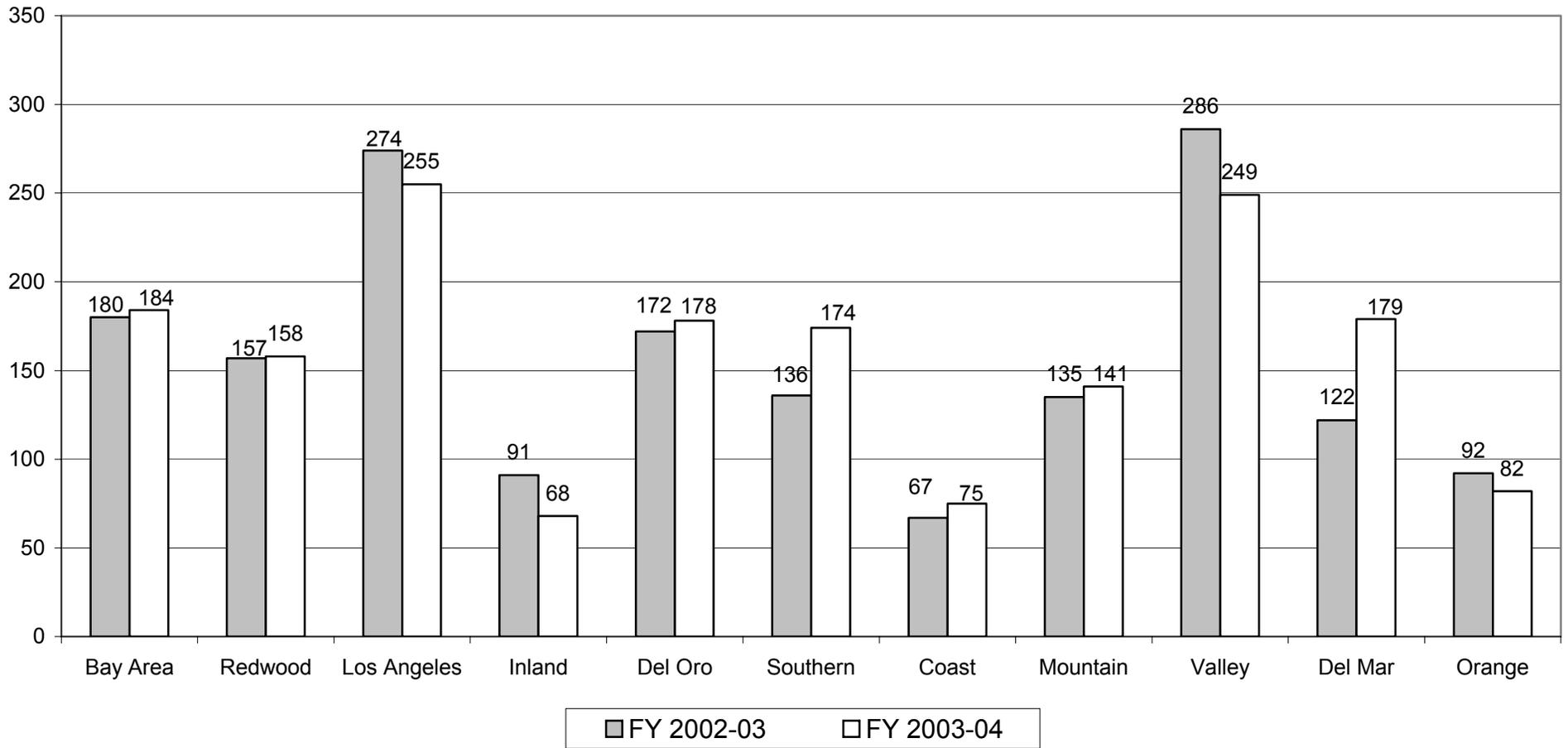
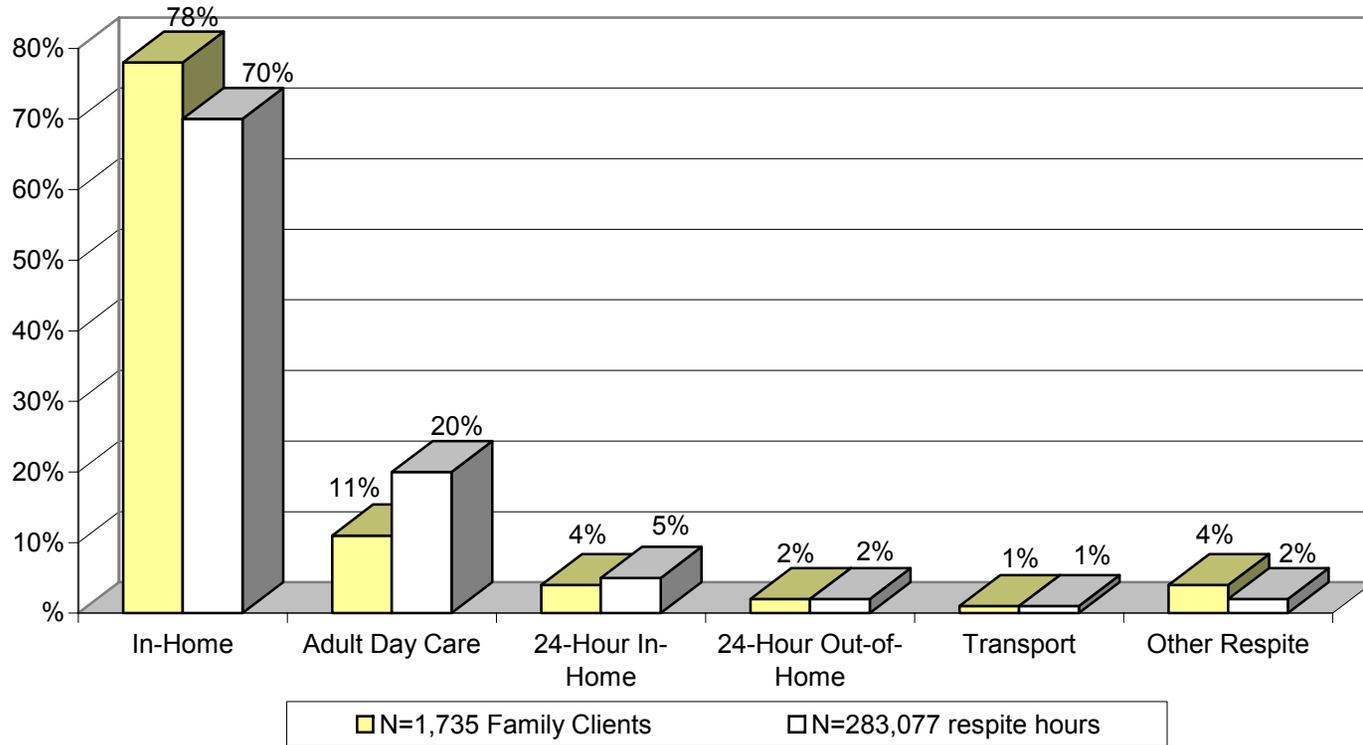
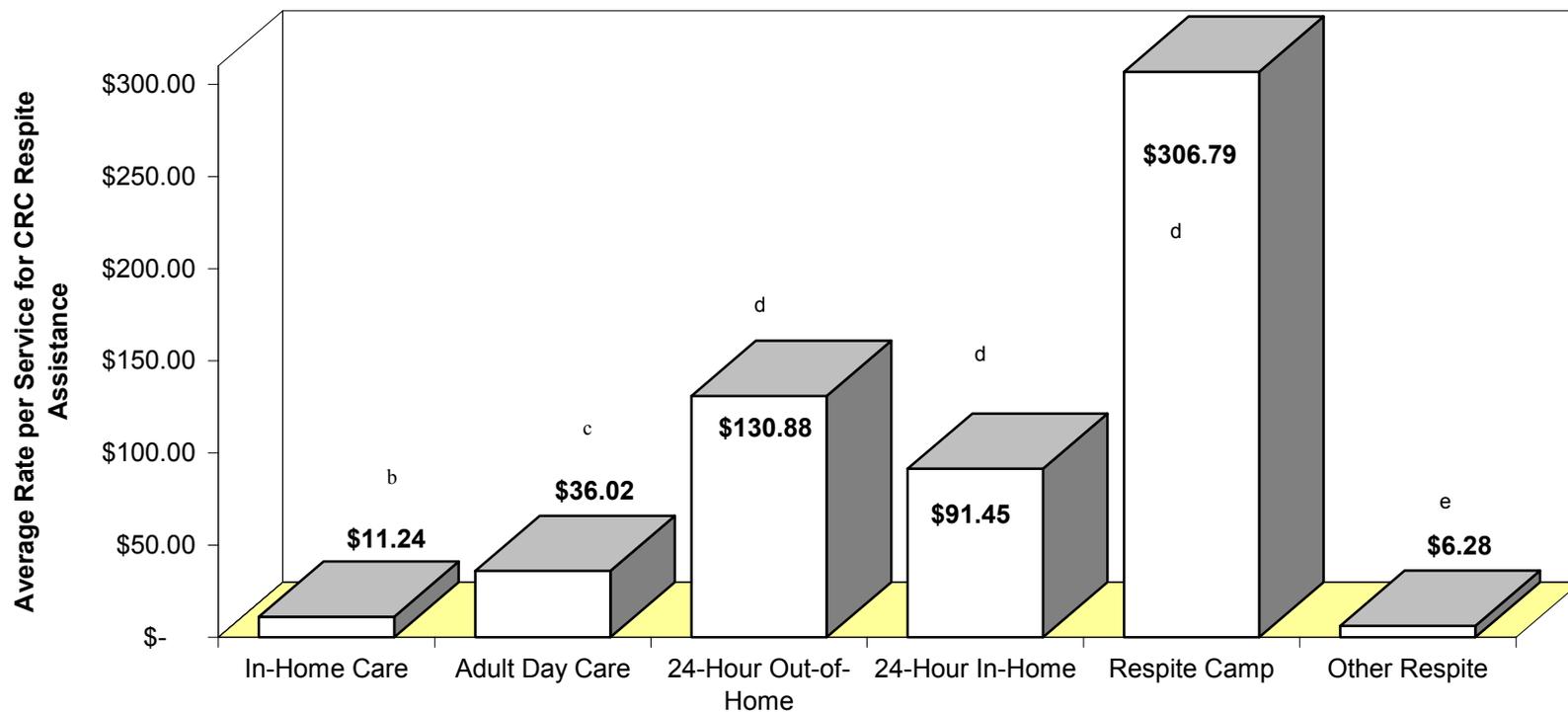


FIGURE 6
CAREGIVER RESOURCE CENTERS
CRC RESPITE USE BY TYPE OF RESPITE:
PROPORTION OF CLIENTS SERVED AND PROPORTION OF HOURS UTILIZED
FY 2003-2004



**FIGURE 7
CAREGIVER RESOURCE CENTERS
RESPIRE CARE: AVERAGE RATE PER SERVICE ^a
FY 2003-2004**



^a Excludes client co-payments.

^b Per hour.

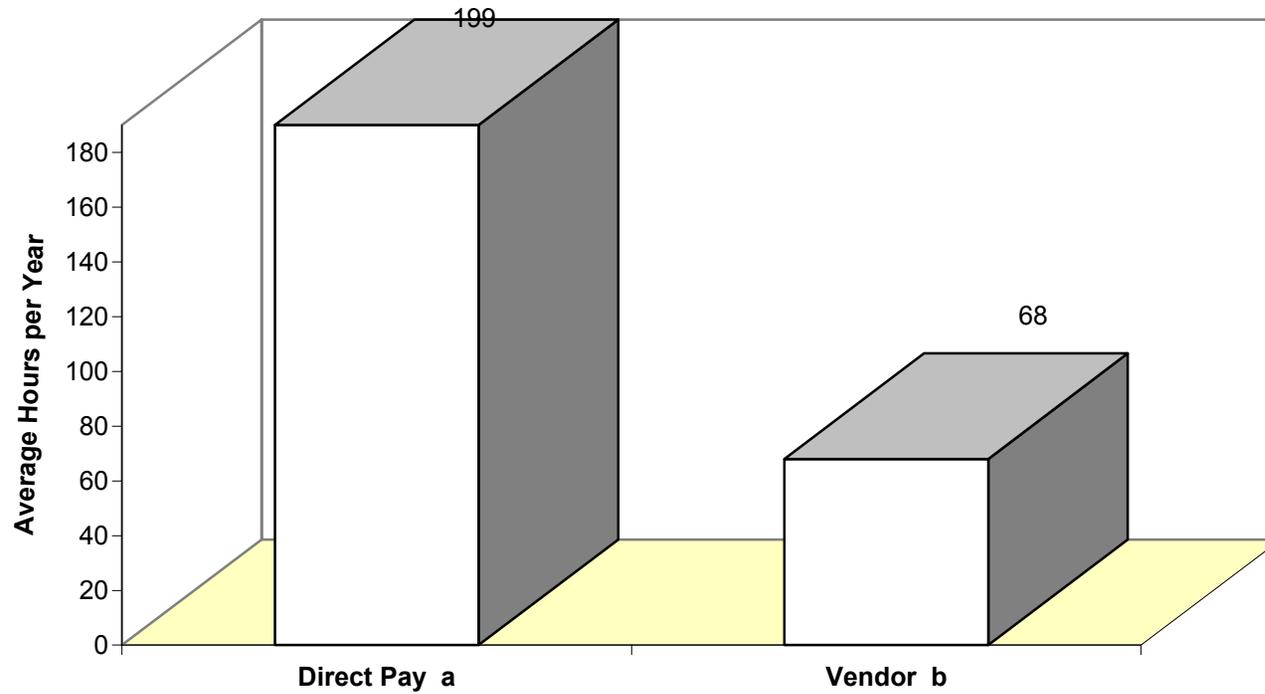
^c Per 7-hour day

^d Per 24-hour day

^e Group respite per four hour day (average of 4-9 participants per group).

Note: The average rate per service is calculated by using the total respite expenditures for a type of respite service and dividing by the total units of service provided for a type of respite service.

FIGURE 8
CAREGIVER RESOURCE CENTERS
IN-HOME RESPITE CARE – AVERAGE AMOUNT OF SERVICE IN HOURS PER CLIENT:
VENDOR AND DIRECT PAY
FY 2003-2004

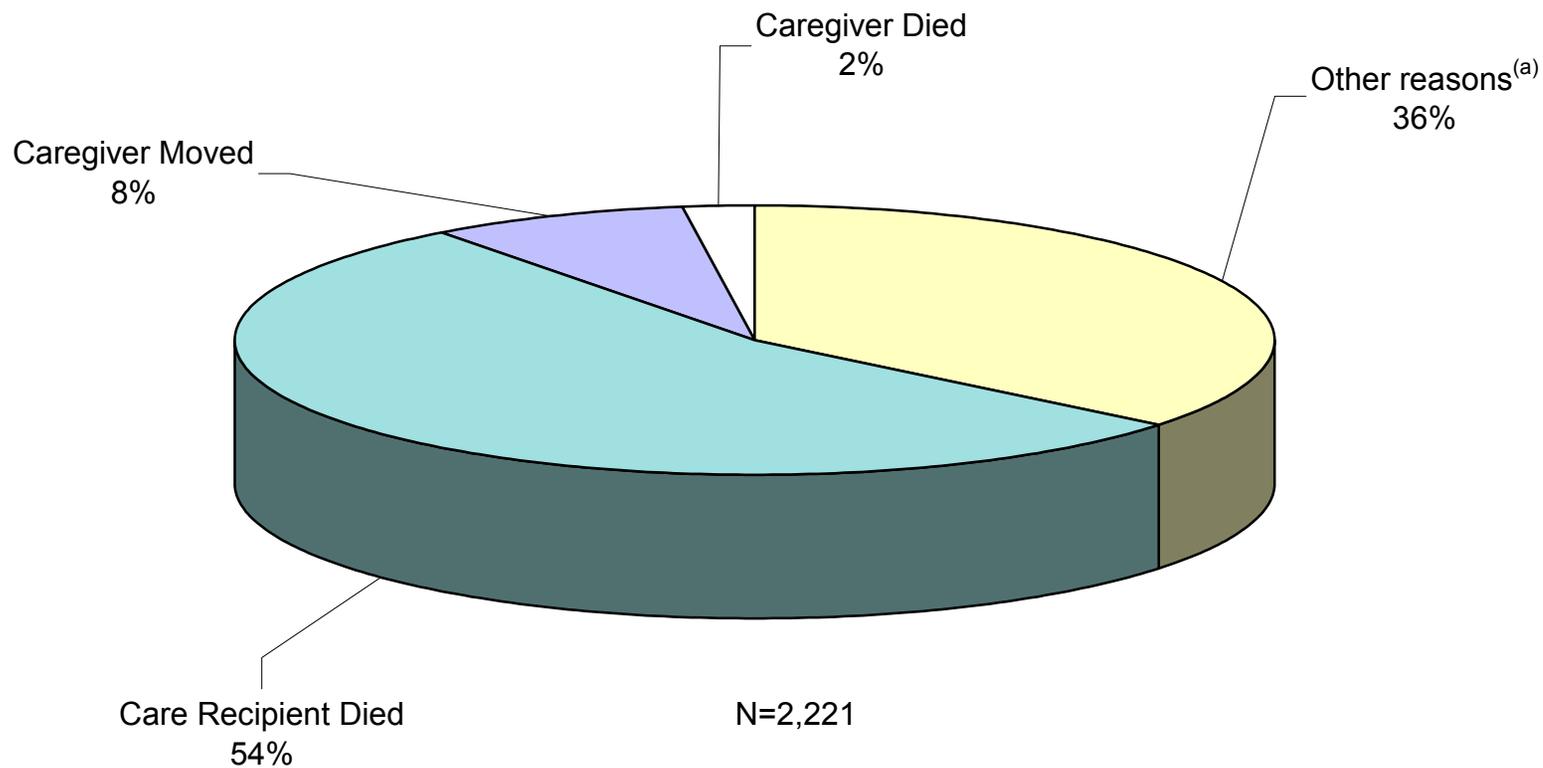


^a Based on 153,090 hours divided by 771 direct pay respite (in-home) clients.

^b Based on 47,567 hours divided by 700 vendor respite (in-home) clients.

NOTE: Some families use more than one type of respite. Therefore, the sum of the clients using both direct pay and vendor respite may exceed the total number of clients receiving in-home respite.

FIGURE 9
CAREGIVER RESOURCE CENTERS
PERCENT OF CASES CLOSED BY REASON
FY 2003-2004



^a "Other Reasons" include families who declined further services or who could not be reached for a reassessment.

FIGURE 10
CAREGIVER RESOURCE CENTERS
PERCENT OF ADULTS WITH BRAIN IMPAIRMENT PLACED IN A
RESIDENTIAL FACILITY BY FACILITY TYPE
FY 2003-2004

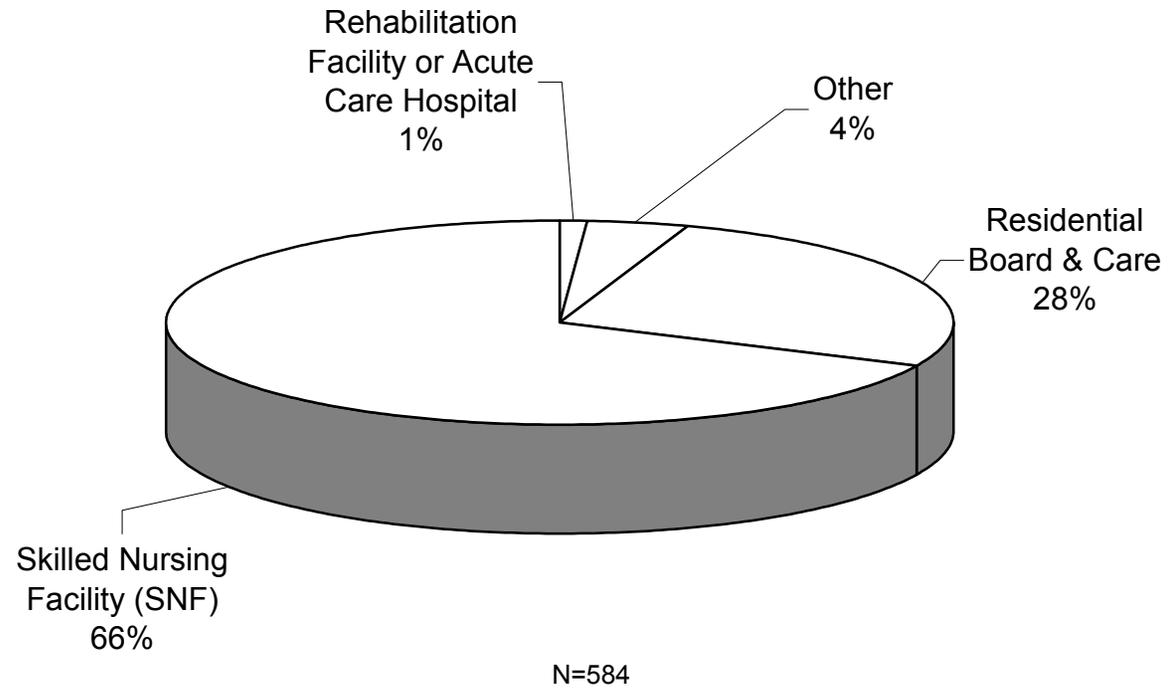
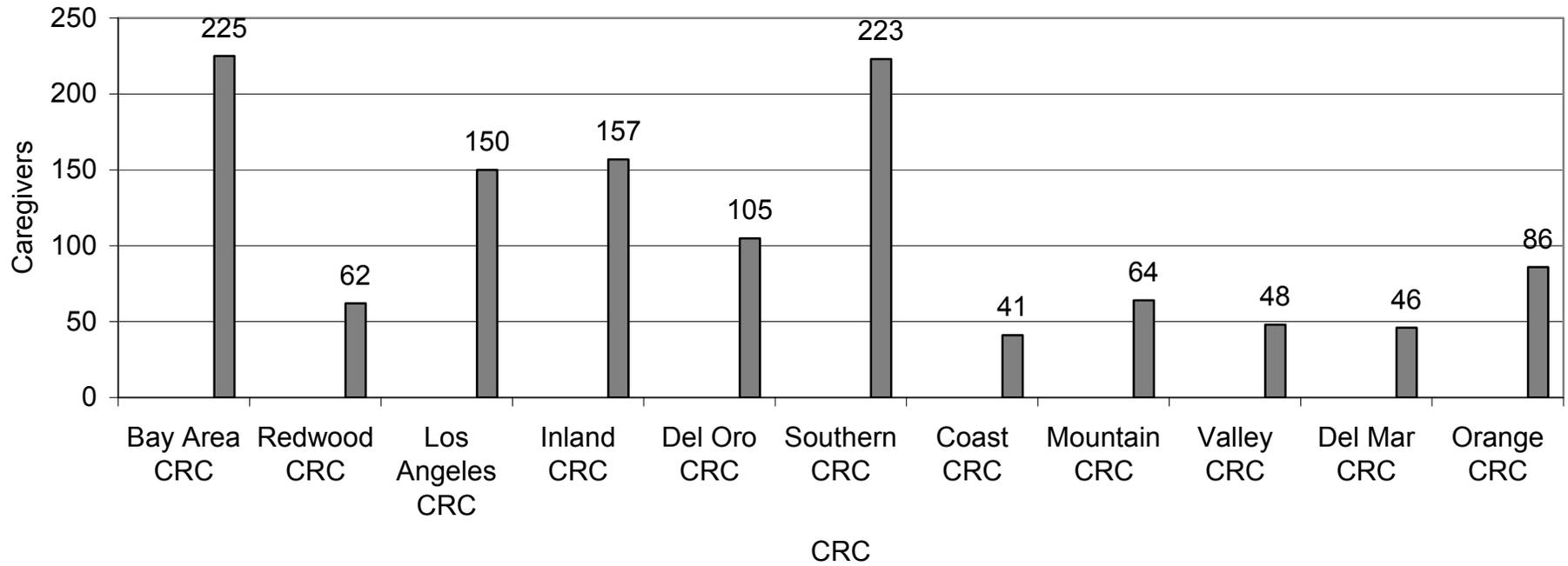


FIGURE 11
CAREGIVER RESOURCE CENTERS
LINK 2 CARE
ACTIVE CAREGIVER ENROLLMENT BY CRC
OCTOBER 2004



CALIFORNIA'S CAREGIVER RESOURCE CENTERS SITE DISTRIBUTION LIST

| Site Number, CRC, and Counties Served | Host Agency | Program Information |
|--|--|---|
| <p>(01) BAY AREA CRC</p> <p>Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara</p> | <p>Family Caregiver Alliance Kathleen Kelly Executive Director 180 Montgomery St., Suite 1100 San Francisco, CA 94104 (415) 434-3388 (800) 445-8106 E-Mail: kkelly@caregiver.org</p> | <p>Donna Schempp, LCSW Director, Programs and Services 180 Montgomery St., Suite 1100 San Francisco, CA 94014 (415) 434-3388 (800) 445-8106 (statewide) FAX: (415) 434-3508 E-Mail: info@caregiver.org Web: www.caregiver.org</p> |
| <p>(02) REDWOOD CRC</p> <p>Del Norte, Humboldt, Lake, Mendocino, Napa, Solano, Sonoma</p> | <p>North Coast Opportunities, Inc. Ernie Dickens Executive Director North Coast Opportunities, Inc. 43 North State Street Ukiah, CA 95482 (707) 462-1954 (800) 606-5550</p> | <p>Nancy Powers-Stone Program Director Redwood Caregiver Resource Center 141 Stony Circle, Suite 200 Santa Rosa, CA 95401 (707) 542-0282 (800) 834-1636 (regional) FAX: (707) 542-0552 E-Mail: nps@redwoodcrc.org Web: www.redwoodcrc.org</p> |
| <p>(03) LOS ANGELES CRC</p> <p>Los Angeles</p> | <p>University of Southern California Andrus Gerontology Center Bob Knight, Ph.D. Faculty Liaison Leonard Davis School of Gerontology 3715 McClintock Avenue – MC 0191 Los Angeles, CA 90089-0191 (213) 740-5156</p> | <p>Donna Benton, Ph.D. Director Los Angeles Caregiver Resource Center 3715 McClintock University Park, MC-0191 Los Angeles, CA 90089-0191 (213) 740-1376 (800) 540-4442 (regional) FAX: (213) 740-1871 E-Mail: benton@usc.edu Web: www.usc.edu/lacrc</p> |

| Site Number, CRC, and Counties Served | Host Agency | Program Information |
|--|---|---|
| (04) INLAND CRC Inyo, Mono, Riverside, San Bernardino | Inland Caregiver Resource Center Robert Jabs, Ph.D. President, Board of Directors 1420 E. Cooley Dr. Suite 100 Colton, CA 92324 (909) 514-1404 | David Fraser Executive Director Inland Caregiver Resource Center 1420 E. Cooley Dr. Suite 100 Colton, CA 92324 (909) 514-1404 (800) 675-6694 (CA) FAX: (909) 514-1613 E-Mail: dfraser@inlandcaregivers.org |
| (05) DEL ORO CRC Colusa, Sutter, Yuba, Sierra, Nevada, Placer, El Dorado, Amador, Alpine, Calaveras, San Joaquin, Sacramento, Yolo | Del Oro Caregiver Resource Center Gerri Hopelain President 5723A Marconi Ave. Carmichael, CA 95608 (916) 971-0893 | Janet E. Claypoole Executive Director Del Oro Caregiver Resource Center 5723A Marconi Avenue Carmichael, CA 95608 (916) 971-0893 (800) 635-0220 (regional) FAX: (916) 971-9446 E-Mail: jclaypoole@deloro.org Web: www.deloro.org |
| (06) SOUTHERN CRC San Diego, Imperial | Southern Caregiver Resource Center, Inc. Craig Homer President, Board of Directors 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432 | Lorie Van Tilburg Executive Director Southern Caregiver Resource Center 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432 (800) 827-1008 (regional) FAX: (858) 268-7816 E-Mail: lvantilburg@caregivercenter.org Web: www.scrs.signonsandiego.com |
| (07) COAST CRC San Luis Obispo, Santa Barbara, Ventura | Rehabilitation Institute at Santa Barbara Scott Silic Vice President of Operations/CFO 2415 De La Vina Santa Barbara, CA 93105 (805) 687-7444 | John Gaynor Director Coast Caregiver Resource Center 5350 Hollister Avenue, Suite C Santa Barbara, CA 93111 (805) 967-0220 (800) 443-1236 (regional) FAX: (805) 967-5060 Email: jgaynor@coastcrc.org Web: www.coastcrc.org |

| Site Number, CRC, and Counties Served | Host Agency | Program Information |
|---|---|--|
| (08) MOUNTAIN CRC Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity | CSU Chico Research Foundation Jeanne Thomas, Ph.D. Chair, Center Policy Board California State University, Chico Chico, CA 95929-0450 (530) 898-6171 | Susanne Rossi Program Director Mountain Caregiver Resource Center 2491 Carmichael Dr., Ste. 400 Chico, CA 95928 (530) 898-5925 (800) 955-0878 (regional) FAX (530) 898-4870 E-Mail: smrossi@csuchico.edu Web: www.caregiverresources.org |
| (09) VALLEY CRC Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, Tuolumne | Valley Caregiver Resource Center Chris Morse President, Board of Directors 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154 | Margery Minney Executive Director Valley Caregiver Resource Center 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154 (800) 541-8614 (regional) FAX (559) 224-9179 E-Mail: mminney@valleycrc.org Web: www.valleycrc.org |
| (10) DEL MAR CRC Monterey, San Benito, Santa Cruz | Health Projects Center John O'Brien President, Board of Directors 736 Chestnut Ave., Suite F Santa Cruz, CA 95060 (831) 459-6639 | Robert T. Phillips Project Director Del Mar Caregiver Resource Center 736 Chestnut Ave., Suite F Santa Cruz, CA 95060 (800) 624-8304 (regional) FAX (831) 459-8138 E-Mail: rtp9@earthlink.net Web: www.hpcn.org |
| (11) ORANGE CRC Orange | Saint Jude Medical Center Barry Ross Vice President, Healthy Communities 101 East Valencia Mesa Drive Fullerton, CA 92835 (714) 992-3000 | Claudia Ellano Program Director Orange Caregiver Resource Center 251 East Imperial Hwy., Suite 460 Fullerton, CA 92835-1063 (714) 578-8670 (800) 543-8312 (regional) FAX (714) 870-9708 E-Mail: cellano@stjoe.org Web: www.caregiveroc.org |

**STATEWIDE
RESOURCES
CONSULTANT**

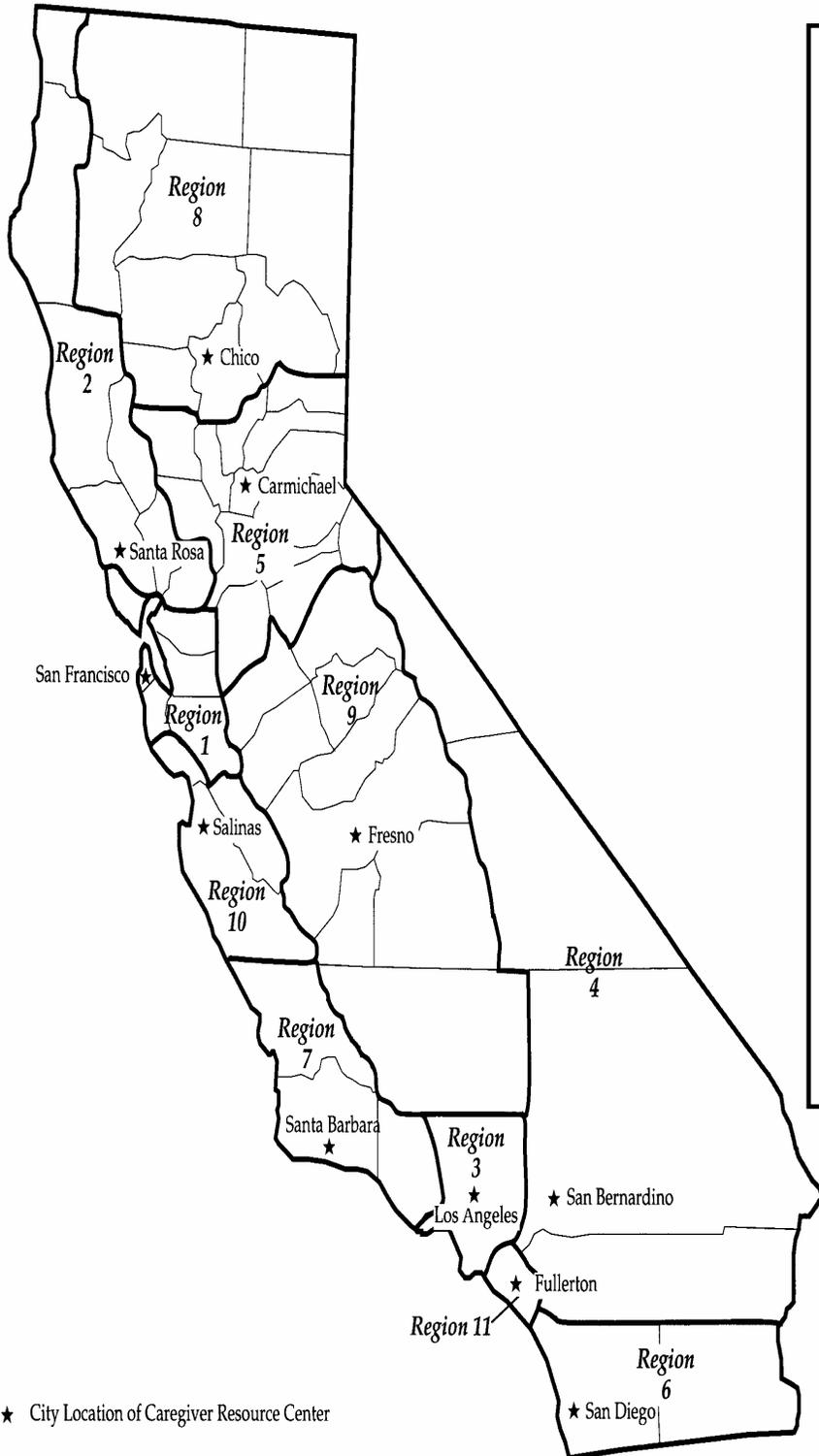
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MAP OF CALIFORNIA'S CAREGIVER RESOURCE CENTERS



★ City Location of Caregiver Resource Center

- REGIONAL CAREGIVER RESOURCE CENTERS AND COUNTIES SERVED**
- 1. Bay Area Caregiver Resource Center/Family Caregiver Alliance**
Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara
 - 2. Redwood Caregiver Resource Center**
Del Norte, Humboldt, Lake, Mendocino, Napa, Solano, Sonoma
 - 3. Los Angeles Caregiver Resource Center**
Los Angeles
 - 4. Inland Caregiver Resource Center**
Inyo, Mono, Riverside, San Bernardino
 - 5. Del Oro Caregiver Resource Center**
Colusa, Sutter, Yuba, Sierra, Nevada, Placer, El Dorado, Amador, Alpine, Calaveras, San Joaquin, Sacramento, Yolo
 - 6. Southern Caregiver Resource Center**
San Diego, Imperial
 - 7. Coast Caregiver Resource Center**
San Luis Obispo, Santa Barbara, Ventura
 - 8. Mountain Caregiver Resource Center**
Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity
 - 9. Valley Caregiver Resource Center**
Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, Tuolumne
 - 10. Del Mar Caregiver Resource Center**
Monterey, San Benito, Santa Cruz
 - 11. Orange Caregiver Resource Center**
Orange

INCIDENCE AND PREVALENCE OF THE MAJOR CAUSES OF ADULT-ONSET COGNITIVE IMPAIRMENT IN THE UNITED STATES AND CALIFORNIA

Many of the diseases and disorders that affect the brain are progressive and their incidence and prevalence increase with age. Caring for those with adult on-set cognitive impairments frequently becomes a 24-hour, 7-days a week role. As the population ages, the need for care and for understanding the impact of these disorders on families is becoming even more pressing. A report released by the Federal Interagency Forum on Aging-Related Statistics,¹ states that 35.8% of those 85 or older have moderate or severe memory impairment. Persons 85 years and older are the fastest growing segment of California's population.² While the total population of California will double between 1990 and 2040, the population aged 85 and older will increase approximately 6-fold, from fewer than 300,000 to over 1.7 million.³

The loss of cognitive and functional abilities affects the individual and his or her family in profound ways. Caring for adults with cognitive impairments is often very stressful and demanding due to memory loss, behavioral and personality changes; chronic care needs and the high costs of care. Caregiving can span decades, can impact both the physical and mental health of the caregiver and can result in extreme economic hardship.

The following tables estimate the incidence and prevalence of the major causes of cognitive impairment in adulthood in the United States in general and in California in particular. The estimates are conservative, excluding rare disorders for which reliable data are not available.

- Table 1 shows an estimated 1.4 million people aged 18 years and older who are diagnosed annually with adult on-set cognitive disease/disorders in the United States (i.e. the incidence).
- Table 2 estimates that between 12.0 and 18.2 million individuals age 18 and over are afflicted with the more common cognitive disorders and diseases diagnosed (i.e. the number of people currently living with the impairment).
- Table 3 looks at the data in comparison to the overall population of the United States and California. An estimated 11% - 19% of the United States and California households may be dealing with the burden of caring for a loved one with an adult on-set cognitive disease/disorder.

Table 1: Incidence of Adult-Onset Brain Disorders⁴

| DIAGNOSIS/CAUSE | PEOPLE DIAGNOSED ANNUALLY |
|----------------------------------|----------------------------------|
| Alzheimer's Disease | 360,000 ⁵ |
| Amyotrophic Lateral Sclerosis | 5,000 ⁶ |
| Brain Tumor | 36,400 ⁷ |
| Epilepsy | 134,000 ⁸ |
| HIV (AIDS) Dementia | 1,196 ⁹ |
| Huntington's Disease | N/A |
| Multiple Sclerosis | 10,400 ¹⁰ |
| Parkinson's Disease | 50,000 ¹¹ |
| Stroke | 750,000 ¹² |
| Traumatic Brain Injury | 85,000 ¹³ |
| TOTAL ESTIMATED INCIDENCE | 1,431,996 |

With over 1.4 million adults diagnosed with a chronic cognitive disease or disorder in the United States annually, the need for both long-term care and support for family caregivers is dramatic. Many of these conditions, for example Alzheimer's disease, stroke, and Parkinson's disease, are associated with increasing age. Given the aging of the United States population, figures will increase proportionately in the coming decades.

Table 2: Prevalence of the Major Causes of Adult-Onset Brain Disorders

| DIAGNOSIS/CAUSE | People Currently Living with the Disorder: Low Estimate | People Currently Living with the Disorder: High Estimate |
|-------------------------------|--|---|
| Alzheimer's Disease | 2,320,000 ¹⁴ | 4,000,000 ¹⁵ |
| Amyotrophic Lateral Sclerosis | 20,000 ¹⁶ | 30,000 ¹⁷ |
| Brain Tumor | 350,000 ¹⁸ | 350,000 ¹⁹ |
| Epilepsy | 1,984,000 ²⁰ | 2,000,000 ²¹ |
| HIV Encephalopathy (dementia) | 14,537 ²² | 58,150 ²³ |
| Huntington's Disease | 30,000 ²⁴ | 30,000 ²⁵ |
| Multiple Sclerosis | 250,000 ²⁶ | 350,000 ²⁷ |
| Parkinson's Disease | 500,000 ²⁸ | 1,500,000 ²⁹ |
| Stroke | 4,000,000 ³⁰ | 4,600,000 ³¹ |
| Traumatic Brain Injury | 2,500,000 ³² | 5,300,000 ³³ |
| TOTAL PREVALENCE | 11,986,537 | 18,218,150 |

Table 2 dramatically illustrates the long-term nature of caregiving for many of these conditions. While it is estimated that 360,000 people are diagnosed with Alzheimer's annually in the United States, there are an estimated 2.32 million people living with the disease many of who require 24-hour care.

Table 3: Select Population Characteristics: United States and California

| | United States | California |
|---|---------------------------|--------------------------|
| Total Population | 284,796,887 ³⁴ | 34,501,130 ³⁵ |
| Total Population 18+ | 211,604,087 ³⁶ | 25,082,322 ³⁷ |
| Total Households | 105,480,101 ³⁸ | 11,502,870 ³⁹ |
| Total Estimated Adults with Brain Impairment | | |
| a. Low Estimate | 11,968,537 ⁴⁰ | 1,418,681 ⁴¹ |
| b. High Estimate | 18,218,150 ⁴² | 2,159,474 ⁴³ |
| Percentage of Adult Population Affected by Brain Impairment | | |
| a. Low Estimate | 5.7% | 5.7% |
| b. High Estimate | 8.6% | 8.6% |
| Percentage of Households Affected by Brain Impairment ⁴⁴ | | |
| a. Low Estimate | 11.3% | 12.3% |
| b. High Estimate | 17.3% | 18.8% |

The 17% figure for the number of households affected by cognitive impairment only begins to elucidate the impact of cognitive impairment upon family caregivers and the long-term care system. With many of these individuals requiring 24-hour care, there are often several family members from different households involved in the caregiving process including spouses, adult children, siblings and friends. Often these caregivers are juggling the responsibilities of caregiving, child rearing and employment simultaneously.

¹ Federal Interagency Forum on Aging-Related Statistics. (2000). *Older Americans 2000: Key indicators of well-being*. Retrieved November 1, 2002, from <http://www.agingstats.gov/chartbook2000/>

² California Department of Aging. (n.d.). *Quick facts: The elderly*. Retrieved October 23, 2002, from http://www.aging.state.ca.us/html/stats/map_narrative.htm

³ California Department of Aging. *The aging baby boomers: Influence on the growth of the oldest old*. Retrieved October 23, 2002, from http://www.aging.state.ca.us/html/stats/oldest_old_narrative.htm

⁴ Due to differences in reporting and data collection, estimates vary and in some cases the figures are for slightly different populations (e.g. aged 13+ or aged 15+) as noted.

⁵ Brookmeyer, R., Gray, S., & Kawas, C. (1998). Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *American Journal of Public Health*, 88, 1337-1342.

⁶ National Institute of Neurological Disorders and Stroke. (2000). Amyotrophic Lateral Sclerosis fact sheet. Retrieved October 22, 2002, from http://www.ninds.nih.gov/health_and_medical/pubs/als.htm

⁷ American Brain Tumor Association. (2002). *Facts and statistics*. Retrieved October 22, 2002, from <http://www.abta.org/primer/facts.htm> (Note: Persons diagnosed with a primary brain tumor.)

⁸ Epilepsy Foundation. (2000). *Cost study shows divide in treatment effect*. Retrieved October 17, 2002 from <http://www.efa.org/epusa/divide.html> (Note: Includes ages 15 and above.)

⁹ Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(No. 2): 18.

¹⁰ National Institute of Neurological Disorders and Stroke. (1996). *Multiple Sclerosis: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/multiple_sclerosis.htm.

¹¹ American Parkinson's Disease Association. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>

¹² National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from http://www.stroke.org/pages/press_disease.cfm

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- ¹³ Centers for Disease Control and Prevention. (1999). *Traumatic Brain Injury in the United States: A report to Congress*. Retrieved October 21, 2002 from <http://www.cdc.gov/ncipc/pub-res/tbicongress.htm> (Note: Estimate for the number of people who experience the onset of long-term disability due to a TBI.)
- ¹⁴ Brookmeyer, R., Gray, S., & Kawas, C. (1998). Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *American Journal of Public Health*, 88, 1337-1342.
- ¹⁵ Alzheimer's Disease and Related Disorders Association, Inc. (n.d.). *Statistics about Alzheimer's disease*. Retrieved November 5, 2002 from <http://www.alz.org/AboutAD/Statistics.htm>
- ¹⁶ National Institute of Neurological Disorders and Stroke. (2000). *Amyotrophic Lateral Sclerosis fact sheet*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/als.htm
- ¹⁷ Amyotrophic Lateral Sclerosis Association. (n.d.). *Quick facts about ALS and the ALSA*. Retrieved October 22, 2002 from <http://www.alsa.org/als/quickfacts.cfm>
- ¹⁸ American Brain Tumor Association. (2002). *Facts and statistics*. Retrieved October 22, 2002, from <http://www.abta.org/primer/facts.htm> (Note: Persons diagnosed with a primary brain tumor.)
- ¹⁹ Ibid.
- ²⁰ Epilepsy Foundation. (2000). *Cost study shows divide in treatment effect*. Retrieved October 17, 2002 from <http://www.efa.org/epusa/divide.html> (Note: Includes ages 15 and above.)
- ²¹ National Institute of Neurological Disorders and Stroke. (2000). *Seizures and epilepsy: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/seizures_and_epilepsy_htr.htm
- ²² Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(No. 2). (Note: Estimated from 1997 data on the percent of individuals developing AIDS-Indicator conditions multiplied by the estimated number of adults/adolescents currently living with AIDS. Overall the CDC reports that the incidence of HIV dementia is decreasing.)
- ²³ Berghuis, J. P., Uldall, K. K. and Lalonde, B. (1999). Validity of two scales in identifying HIV-associated dementia. *Journal of Acquired Immune Deficiency Syndromes*, 21, pp. 134-140. (Note: Based on the high end of their estimate of 7-20% of HIV/AIDS patients developing dementia times the CDC estimate of individuals currently living with AIDS.)
- ²⁴ National Institute of Neurological Disorders and Stroke. (n.d.). *Huntington's disease: Hope through research*. Retrieved on October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/huntington_disease-htr.htm
- ²⁵ Ibid.
- ²⁶ National Institute of Neurological Disorders and Stroke. (1996). *Multiple Sclerosis: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/multiple_sclerosis.htm
- ²⁷ Ibid.
- ²⁸ National Institute of Neurological Disorders and Stroke. (n.d.). *Parkinson's disease: Hope through research*. Retrieved October 22, 2002 from http://www.ninds.nih.gov/health_and_medical/pubs/parkinson_disease_htr.htm
- ²⁹ National Parkinson Foundation. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>
- ³⁰ National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from http://www.stroke.org/pages/press_disease.cfm
- ³¹ American Heart Association. (2002). *2002 heart and stroke statistical update*. Retrieved October 22, 2002 from <http://www.americanheart.org/statistics/>
- ³² National Institutes of Health. (1998). *Rehabilitation of persons with traumatic brain injury. NIH consensus statement online*. 1998 Oct 26-28. 16(1), 1-41. (Note: Estimate includes all ages.)
- ³³ Centers for Disease Control and Prevention. (n.d.). *Traumatic Brain Injury in the United States*. Retrieved October 21, 2002 from <http://www.cdc.gov/ncipc/didop/tbi.htm>
- ³⁴ U.S. Census Bureau. (1999). *Statistical Abstract of the United States: 1999*. Retrieved on October 22, 2002 from <http://quickfacts.census.gov/qfd/states/06000.html> (Note: Population figures for the U.S. and California are projections for the year 2000.)
- ³⁵ Ibid.
- ³⁶ Ibid.
- ³⁷ Ibid.
- ³⁸ Ibid.
- ³⁹ Ibid.
- ⁴⁰ See Table 2.
- ⁴¹ These estimates are based on the percentage of population age 18+ years residing in CA.
- ⁴² See Table 2.

⁴³ These estimates are based on the percentage of population age 18+ years residing in CA.

⁴⁴ Assumes one brain impaired individual per household.