

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, 2002 through June 30, 2003

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ANNUAL REPORT

FISCAL YEAR 2002-2003

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

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TABLE OF CONTENTS

LIST OF TABLES ii

LIST OF FIGURES iii

EXECUTIVE SUMMARY 1

ISSUE 5

BACKGROUND 6

OBJECTIVES 7

METHODOLOGY 9

FINDINGS 10

 Profile of Care Receivers and Family Caregivers 10

 Evaluation Components 12

 The Three Top Needs Identified at Intake (Tables 12 and 13)..... 19

 Other Identified Needs..... 19

 Addressing Identified Service Needs..... 19

 Focus on Link2Care: Merging Support and Technology to Meet Caregiver Needs 1

 Strategic Plan Goals and Achievements 22

RECOMMENDATIONS..... 25

Appendices

A CRC Site Distribution List A-1

B Map of Caregiver Resources B-1

C Incidence and Prevalence of the Major Causes of Adult Onset Brain Impairment,
 United States and California C-1

LIST OF TABLES

<u>TABLE</u>		<u>PAGE</u>
1	Total Clients Served and Average Amount of Service per Client	24
2	Total Clients Served by Service Type	25
3	Direct Services Utilization by Service Type	27
4	Amount of Service per Client by Service Type	29
5	Case Status Summary	30
5b	Caregiver Assessment Return Rates and CES-D Scores by Quarter	31
6	Expenditures for Voucher Services	32
7	Comparison of CRC Respite Voucher Costs and Skilled Nursing Facility Costs	33
8	Hours of Respite Care Provided	34
9	Expenditures for Respite Voucher Services	35
10	Education/Training Activities	36
11	New Unmet Needs/Service Gaps	37
12	Major Needs/Information Requested by Families/Caregivers at CRC Intake	38
13	Major Needs/Information Requested by Providers/General Public at CRC Intake	39

LIST OF FIGURES

<u>FIGURE</u>		<u>PAGE</u>
1	Top Four CRC Services	40
2	Proportion of Family Clients Receiving 1, 2, 3, and 4+ Services	41
3	Average Cost per Year per Client: CRC Voucher Services	42
4	Annual Cost per Client by CRC Site: In-Home Respite and Legal Consultations	43
5	Respite Care by CRC Site: Total Number of Family Clients Served and Amount of Service per Family Client per Week	44
6	Respite Use by Type of Respite: Proportion of Clients Served and Proportion of Hours Utilized	45
7	Respite Care: Average Rate per Service	46
8	Respite Care: Average Amount of Service per Client: Vendor and Direct Pay	47
9	Percent of Cases Closed by Reason	48
10	Number of Adults with Brain Impairment Placed in a Residential Facility by Facility Type	49
11	Link2CareActive Caregiver Enrollment by CRC	50

EXECUTIVE SUMMARY

This report addresses the progress of the *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults*¹ between July 1, 2002 and June 30, 2003. This time period marks the eighteenth 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 2002-03. During FY 2002-03, 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 2002-03:

- Client intake increased *16%* from FY 2001-02 (from 6,526 to 7,581). Approximately *50%* of those completing intake went on to receive additional CRC services.
- Client follow-up information and referral increased *25%* FY 2001-02, client reassessment and family consultation increased *9% and 10%* respectively over the same period.
- The total number of individuals receiving at least one CRC service increased *13%* from FY

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.

2001-02 (from 14,475 to 16,379) while the number of families receiving CRC respite assistance fell 7% from 1,841 to 1,712 over the same period.

- Most family caregivers received an average of 4.4 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 \$2,897,506 or an average of \$3,818 per family caregiver who received respite per year. The average monthly cost per family caregiver was \$332, of which \$313 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 over *10 times* the average monthly cost of CRC respite services. The average monthly private pay nursing home cost is over *13 times* (\$4,415 in 2003) the average monthly cost of CRC respite services.
- **Respite is a primary need for caregivers. The average client wait time for CRC respite assistance is 23 months. At the end of FY 2002-03, 4,281 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 75 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 12.2 hours of care per day – more than a full-time job.
- Caregivers receive only an average of 1.6 hours of help per day from family or friends. Close to 7 out of 10 (67%) caregivers feel they receive “far less” and “somewhat less” help from family or friends than they need.
- One-third (31%) of caregivers reported feeling “depressed,” while 56% were scored as “depressed” using the Center for Epidemiological Studies Depression Scale (CES-D). Overall, 44% report high burden levels, and 44% of the caregivers say their physical health is now worse than five years ago.

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

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 2002. See the Methodology section for more detailed information.

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. In fact 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 caregivers 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 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, 2002 through June 30, 2003.

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, Statute 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.

Phasing-In of CRC Sites

Implementation began in FY 1984-85 with continuation of Family Caregiver Alliance as the first CRC serving the greater San Francisco Bay Area. DMH also awarded the contract for the SRC to Family Caregiver Alliance in 1985. All eleven regional CRC sites were operational by 1989. **In FY 2002-03, 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 months and 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;**
- **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;** and
- **Respite care services** through the flexible and creative use of local resources including: home care, adult day care services; foster and group care; transportation; and temporary placement in a residential facility.

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 2001 calendar year is presented in the Findings Section.

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 23-50). Last, an outline of the CRC System Strategic Plan Goals and achievements are presented with recommendations to meet caregiver needs for FY 2002-2003.

Profile of Care Receivers and Family Caregivers⁶

A. Selected Care Receiver Characteristics:

Care receivers are typically older, ranging in age from 18 to 101 years old, with an average age of 76. *Ninety percent* of care receivers are age 60 and older. *Eighty-five percent* are at least 65 years of age; *66%* are 75 years of age and older; and *23%* are at least age 85.

Care receivers are more likely to be female (*54%*) than male (*46%*). They generally live with their spouse only (*47%*), or with their spouse and/or others (*38%*). Comparatively few care receivers live alone (*9%*) or in nursing homes (*1%*) when the caregiver first calls the CRC for assistance.

The median household income range for the care receiver population in 2002 was between \$20,000 and \$25,999, barely half of California's median income in 2002 of \$49,738.⁷

Sixty-eight percent of care receivers have a dementing illness, principally Alzheimer's disease (*32%*), but also Parkinson's disease (*8%*), Huntington's disease (*3%*), and other dementias/degenerative diseases (*24%*). *Twenty-two percent* had a stroke, *3%* are traumatic brain injury survivors, and *4%* 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-seven percent* of care receivers experienced the onset of disease/disorder within a range of three to ten years. *Ten percent* of the population has lived with their cognitive disease/disorder for 11 years or longer.

Thirty-two percent of the care receivers have out-of-pocket health care expenses. *Forty-seven percent* are enrolled in a health maintenance organization (HMO).

⁶ CRC Uniform Assessment Database 2002 (N = 2,243 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 Commnity Survey, California, 2002.

Problem Behaviors Associated with Brain Impairment:

These care receivers have particularly heavy care needs. As reported by their caregivers, they average eight memory and behavior problems, commonly related to the individual's cognitive deficits (e.g., communication, concentration), and nine functional problems related to inability to perform daily tasks (e.g., bathing, feeding, dressing; using the telephone, and performing chores).

Nearly three quarters (71%) of care receivers are unable to perform three to five activities of daily living (ADLs) and 20% cannot perform one or two ADLs. Approximately seven in ten (72%) cannot be left alone and need constant supervision. Another 41% wake their caregiver at night, and 52% are incontinent.

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 94 years with an average age of 61. Fifty percent of the caregivers are 60 years of age or older. Twenty-one percent are 75 years of age and older. Twenty-one percent are between the ages of 36-50 years.

Caregivers served by CRCs are typically spouses (45%), while 40% are adult children and 15% have another relationship to the care receiver. Family caregivers are most likely to identify themselves as the "primary" caregiver (96%) and to live with the care receiver (82%).

The majority of family caregivers served by the CRCs are white (77%), 10% are Hispanic, 7% are African American, 4% are Asian/Pacific Islander, and 2% are reported as other ethnic groups.

Half (50%) of the caregivers under the age of 65 also work outside the home, either in full-time (33%) or part-time (17%) jobs.

Caregiver Well-Being:

Depression is a serious problem for family caregivers. Nearly six in ten (56%) 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 one-third (31%) of caregivers self-report feeling "depressed." Overall, about 35% of caregivers report burden of care that ranges from "quite a bit" to "extreme," 71% report significant health problems, and 44% of the caregivers say their physical health is now worse than five years ago.

Caregiver Social Support:

Family caregivers served by CRCs report that they provide an average of 84 hours of care a week to their care receiver, or an average of about 12 hours per day. By comparison, these

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

caregivers receive only 11.1 hours per week (or 1.6 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.

Caregiver Service Needs:

The greatest caregiver needs, reported by caregivers, at intake, were for respite care (76%), emotional support (73%), and general information/orientation (70%). *Twenty-five percent* of caregivers needed assistance with financial advice and aid, 23% needed legal assistance, and 21% managing the care receiver's behavioral problems.

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 51% in FY 2001-02 to 58% in FY 2002-03. The proportion of family caregivers utilizing two services decreased to 32% from 37% in fiscal year 2001-02, and the proportion of family clients using three or more services decreased to 8% from 14% in FY 2001-02 (Figure 2).

During FY 2002-03, **a total of 16,379 family caregivers utilized one or more services** at the eleven CRC sites in California, *a 13% increase* over the previous year (FY 2001-02). Of these, **14,303 (87%) received core CRC services** (i.e., services beyond just information or assessment). The average service use per client across all CRC core services was 26 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 4.4 hours of service per year (Table 1). **A total of 13,993 family caregivers had active cases**¹⁰ during at least some portion of FY 2002-03, *a 43% increase* over the previous fiscal year (Table 5).

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.

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 2002-03. Table 6 and Figure 3 show voucher service expenditures.

A total of 7,581 family caregivers¹¹ completed the intake process across the eleven CRC sites, *a 16% increase* over the previous fiscal year. Additionally, during this fiscal period, **6,071 caregivers received an average of .8 hours of follow-up information** during the current fiscal year (Tables 2 and 4).

A total of **3,939 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. Approximately half (50%) of caregivers completing intake went on to be assessed. The number of in-home assessments conducted during FY 2002-03 increased by 2% over the number of assessments conducted during FY 2001-02 (Tables 2 and 5b).

A total of **4,335 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 decreased overall by 9% from the previous fiscal year.

A total of **11,286 family caregivers received an average of 2.5 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 **15,974 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 901 caregivers received an average of 9 hours of emotional support and information exchange through attendance at CRC-sponsored support groups. A total of **349 caregivers attended psychoeducational groups**, offered by ten CRCs. Caregivers received an average of 19.6 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 287 caregivers received an average of 4.1 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 \$276 for four one-hour sessions (Tables 2, 4, and 6).

¹¹ Another 1,102 service providers and members of the general public also completed a CRC intake during FY 2002-03 (Table 13).

¹² Another 4,215 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).

A total of 332 caregivers received an average of 1.2 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 \$115 (Tables 2, 4, and 6). Regional variations in legal consultation costs at CRCs are shown in Figure 4.

A total of 1,712 family caregivers received CRC **respite assistance**, receiving an average of about 400.8 hours of respite during the year (Tables 2 and 4). The proportion of family caregivers receiving respite services decreased 7% this fiscal year, compared to fiscal year 2001-02, due to 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 (76% and 73%, respectively). This level of need is related to the strain these families experience:

- *Twenty-nine percent* of caregivers feel moderately burdened, *30%* feel burdened quite a bit, and *14%* feel extremely burdened; *16%* percent indicate that they felt 'a little' burdened.
- *Twenty-eight percent* of caregivers rate their overall health as fair to poor, and *44%* say their physical health is now worse than five years ago.
- **Caregiver depression is high: 56% 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 2002-03, the eleven CRCs provided a total of 309,054 hours of respite care to 1,712 families (Tables 8, Figure 5). About 771 families, on average, received respite services each month at the eleven CRCs (or 70 families per site per month).

- On average, caregivers received eight hours of respite care per week (Table 8).
- Among caregivers using in-home respite, 55% used the “direct pay” in-home respite; fewer (47%) used the vendor in-home respite option.¹³
- Because of the lower cost of "direct pay" in-home respite, **caregivers utilizing the direct-pay option received three times as much service**—(225 hours vs. 74 hours) on average, per family caregiver (Figure 8).
- The annual expenditure for respite care voucher services at the eleven CRCs was \$2,897,506 or an average of \$3,758 per family caregiver per year (Table 9).
- The total expenditures for CRC respite care services *including family caregiver share of cost* was \$3,169,300 or \$3,987 per family caregiver per year (Table 9).
- On average, over **two thirds (69%) 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 \$271,794 or 9% 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 \$332**; \$313 was provided by the CRCs. Family caregivers contributed, on average, an \$19 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 4,281 California family caregivers remained on CRC respite wait lists at the end of the FY 2002-03 (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 23 months on a respite waiting list before receiving CRC respite assistance** (Table 3).

Throughout the fiscal year, a total of 3,973 cases were closed. **Of cases closed providing a reason, one-third were closed due to the care receiver’s death (32%); in 6% of the cases, the caregiver died or moved. A total of 564 family caregivers reported placing their relative in a residential facility (primarily in a skilled nursing facility) during FY 2002-02** (Table 5, Figures 9 and 10). Since caregivers are on CRC respite waiting lists for an average of 23 months, invariably some caregivers experience the death or institutionalization of care receivers

¹³ Some families use more than one type of respite. Therefore, the sum of the total percentages for individual types of respite exceeds 100 percent.

prior to receiving respite services.

Respite services alone may not meet the multi-faceted needs of family caregivers. At the time of assessment, approximately six 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. S's and Mrs. T's story show the difference caregiver support makes:

Mr. S's wife of 60 years had a stroke in 2001. This was such an emotional experience for this couple that had spent many happy years traveling and enjoying each other's company. Mr. S heard about Southern Caregiver Resource Center from an adult day care fair and contacted us for assistance. At this time he really never knew what he could gain from such a program.

Mr. S is a very active man. He attends a support group for men that Southern Caregiver Resource Center offers. He has meet friends in this group that will be there for life. Mr. S calls himself the greeter for the support group now. He will make sure each new person attending the group feels welcome and supported. Many of the men, including Mr. S, will go out for lunch after the group is over to provide each other with additional support. Recently, I met with Mr. S to discuss how things were going for him. He stated that he is having difficulty spending time with his wife due to her short-term memory loss and her asking the same question over and over again. I suggested that he share the couple's past experiences with his wife. Mr. S has traveled all over the world. Mr. S's face lit up when I was talking with him about the idea of bringing up a past topic or event to talk about with his wife. Not only did our conversation result in Mr. S feeling excited to see his wife and talk about all of their happy memories, but it also reminded him to be grateful for each day of his life and everything that it has to offer him. Through Southern Caregiver Resource Center, Mr. S has gained friendship, emotional support and a place where he can turn to whenever he needs it.

It's remarkable to watch a caregiver transform over the period of eight months. This is a story of the changes Mrs. T has undergone and the Southern Caregiver Resource Center has played in this process. In January 2003, Mrs. T, a 67-year-old caregiver, first noticed short-term memory loss in her 70-year-old husband. Mr. T's memory deficits appeared shortly after a quadruple bypass surgery. At the time, Mrs. T was feeling lost and unsure about what to do. Following

our first meeting, Mr. T was evaluated and diagnosed as having Vascular Dementia. This was also attributed to Mr. T's diabetes and numerous transient ischemic attacks (TIAs). Through our conversations, Mrs. T learned about Vascular Dementia and began understanding her husband's change in behavior. This was a difficult time for Mrs. T, who also had her own health concerns including Chronic Obstructive Pulmonary Disease (COPD) and arthritis.

Realizing she needed to build her support system, Mrs. T joined one of Southern Caregiver Resource Center's caregiver support groups. This particular group meets weekly, which is what she needed. Mrs. T learned from other caregivers, some of whom had up to 12 years of experience in family caregiving, that she was not alone. Within the next month, Mrs. T participated in a six week psycho-educational class called "Taking Care of You: Powerful Tools for Caregiving." This experience allowed her to not only learn useful skills and techniques, but also to discover how to take care of herself. Eight months after our initial meeting, Mrs. T continues attending the Caregiver Support Group in which she offers advice to other members. The funny thing is that she still refers to herself as the "new one," yet many times she imparts her experience to others. Mrs. T often mentions our first meeting and how she was so lost. "If it weren't for Southern Caregiver," commented Mrs. T, "I might still be lost."

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. S's and Mrs. T'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 average monthly cost for a Medi-Cal patient in a California skilled nursing facility was \$3,423 in fiscal year 2002 — over 10 times the \$332 average monthly cost of CRC respite services. Private pay nursing homes cost residents over 13 times (\$4,415 per month) the cost of CRC respite (See Table 7 for Medi-Cal and private pay rate references).

As previously noted, during FY 2002-03, CRCs spent \$2,897,506 providing respite assistance to a total of 1,712 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 \$70 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**

¹⁴ Based on \$41,076 annualized 2002 SNF Medi-Cal rate x 1,712 persons.

savings.

While it may not be appropriate in some very difficult cases for family to continue providing care at home, CRC services help many families who are deciding 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 4,281 families on CRC respite waiting lists, some care receivers will be placed in a nursing home before CRC respite services became 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 Mr. G's caregiving example:

Mr. G's daughter first contacted Bay Area Caregiver Resource Center in 2001 after learning about our services through the website. Her mother, Mrs. G, was suffering from dementia and had been diagnosed with Alzheimer's disease. Both of her parents were attending a support group through the Alzheimer's Association. They were most concerned that the patient would wander away if she was not watched at all times, therefore Mr. G was unable to get away to do errands, go to the doctor for himself or get a break. Bay Area CRC referred the family to an Alzheimer's Diagnostic Center where Mrs. G was eventually diagnosed as having vascular dementia. This helped the family to know what to expect and what Mrs. G could and could not do.

A year after Bay Area CRC first started to help Mr. G, he called the office for help in handling his wife because she was becoming less cooperative. Bay Area CRC recommended he attend one of our psychoeducational classes and he enrolled in "Controlling Frustration" taught by the family consultant. He said this helped him to not see his wife's behavior as intentional, as he thought she was being passive aggressive. With his son's encouragement, Mr. G hired a caregiver in the morning to get his wife up and ready for daycare as she was becoming more resistant to getting dressed. He also enrolled his wife in the Bay Area CRC Camp for Caring for the weekend so that he may enjoy a vacation. In September 2003, Mr. G placed his wife in a dementia facility after she fell and broke her arm. Even though his wife is now in a facility, he requested that Bay Area CRC continue to keep in contact with him because having someone checking in has been encouraging. In April 2002, Mr. G wrote a note saying "You have been very helpful and supportive in my new venture of dealing with my wife's dementia. I thank you and enclose a check to help support your efforts."

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

- 1) **Nearly seven out of ten (71%) family caregivers and 44% of service providers/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) **More than half (65%) of the caregivers and 29% of service providers¹⁵ indicated a need for respite care services.**
- 3) **Emotional support was a key need for well over half (63%) of families and 18% of service providers.** 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.

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 2002-03 in their respective regions. The most common needs included: a greater availability of respite care services, services for traumatic brain injury survivors, support groups (bilingual and available to working caregivers), adult day care, and a range of services in languages other than English.

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 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.

¹⁵ Respite needs identified by service providers indicate respite for the family caregiver.

The 11 CRCs provided family-focused educational seminars and workshops for 15,974 CRC family clients and professionals. This represents a 24 % increase in attendance from FY 2001-02. During FY 2002-03 31,519 participants attended conferences and other educational events held regionally and statewide on issues related to caregiving and adult-onset cognitive impairments. This figure dropped 16% 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, enjoyed significant growth this year. Moving from demonstration project to statewide implementation, caregiver enrollment in Link2Care grew 135% during the last year, up from 300 in 2002 to over 700 enrolled in 2003. The Link2Care website and discussion group are now available throughout California. Coast CRC began offering Link2Care to their service area July 03. Although the program receives frequent inquiries from out-of-state caregivers, Link2Care remains a strictly California-based service.

Who Uses Link2Care?

Link2Care is an example of a privately funded (The California Endowment) demonstration project being replicated throughout a statewide services system. In December 2002, a Caregiver Satisfaction Survey was sent electronically to all Link2Care participants. Ten of eleven CRCs were participating in Link2Care at the time of the survey. As of July 2003, all eleven CRCs are offering Link2Care as a client services.

Users of the Link2Care program reflect national statistics on caregiver groups. Program caregivers are primarily women (75%) with carers who are a daughter (39%), wife (26%), husband (15%), son (8%), 3% daughter-in-law and 10% other (friend, other relative). Survey results showed that family caregivers are ready to embrace computer Internet technology to help them care.

Ninety-eight percent of surveyed Link2Care users said that having caregiver support available on the Internet provides support. The majority (85%) of respondents indicated they would probably or definitely recommend L2C to other caregivers. *Sixty percent* said L2C helped them cope with caregiving issues with an equal number saying L2C helped to reduce feelings of isolation. In rating L2C features, 70% find the Caregivers News/Caregiver Links, Information Articles and Fact Sheets as useful to very useful. 62% rate the Discussion Group as a favorite feature, with 48% appreciating the Events listing and 29% favoring the personal journal.

What Do Users Think About Link2Care?

Examples of what surveyed caregivers said they like most about L2C: "Knowing that I'm not alone," "Knowing it's there when I need it," "Ask the Expert," "It has lots of information," "[I found it helpful] learning how others handle difficult situations." Caregivers were split 50-50 about their sense of comfort in having L2C (discussion group and site) only available to those in California. Half said it increased their comfort, while the other half saying it made no difference. Ninety-eight percent of caregivers agreed that having caregiver support available on the Internet is helpful. Reflective of many of the comments received, caregivers said, "We ALL need services such as these to help inform and support our efforts to be good caregivers!" "Thank you for your work. It [Link2Care] has been very helpful to my family. Keep it

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 for 2002-2003. Below are the identified system goals for the year and accompanying accomplishments.

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

Background Information: The National Family Caregiver Support Program (NFCSP) was established with the enactment of the Older Americans Act Amendments of 2000. The program establishes services for family caregivers in the following areas: information about available services, assistance in gaining access to supportive services, individual counseling, organization of support groups, and caregiving training to assist the caregivers in making decisions and solving problems relating to their caregiving roles; respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities, and supplemental services to complement the care provided by the caregivers. The NFCSP is administered in California through the 33 Areas Agencies on Aging (AAAs) of the California Department of Aging.

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.

- Bay Area CRC staff visited with California legislators to provide them information on FCA services and caregiving issues.
- Throughout the state, CRC staff members were active in addressing the needs of family caregivers at public forums and Advisory Council Meetings by working in collaboration with AAAs in their respective service areas.
- Some CRC's expanded outreach scope by placing aids in local papers and radio broadcasts, extending target population services to caregivers over age 60, 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.

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 135% during the last year, up from 300 in 2002 to over 700 enrolled in 2003.
- A number of the eleven CRCs advanced services to caregivers using Internet Technology. For example, several distributed monthly e-newsletters to cover caregivers and professionals; one developed an online support group for Lesbian/Gay/Bisexual/Transgender clients; and another implemented an advocacy tree with Caregiver Advocates using email and the Internet to disseminate information on caregiver advocacy action issues.
- Several CRCs expanded their websites to links to 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. (See Appendix A for the addresses of these websites.)

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

- The CRC system has began implementing the conversion to a new client record tracking system. The project is expected to be completed by the end of the 2003 fiscal year. Currently the project is in the last phase of testing, documentation and training. Data migration and conversion is scheduled for January 2003.

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, a number of sites purchased laptops, trained staff in technology skills, established Internet access at satellite offices, developed more web-based resources, or made software upgrades to increase efficiencies.

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

- *Redwood CRC* continued to work with ACCESS collaborative, a web-based case management program.
- *Los Angeles CRC* is developing training videos “Ten Essential Tools for Caregivers” and launched “making the Link” physician outreach program in LA county.

- *Del Oro CRC* maintained bimonthly meetings with Nevada County Long-Term Care Integration Council regarding county-wide on-line program to promote referral within senior agencies and reduce fragmentation of services.
- 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.)

- CRC directors explored purchasing employee benefits (e.g. health insurance) as a statewide system in order to obtain better coverage at lower rates. Several CRCs worked with their host agencies to negotiate the cost-effective purchasing of products and services. CRC staff also established pilot cooperative agreements with other community agencies to share information and strategies as well as outreach costs.

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

- Several CRCs added positions to enhance education and training services under both Chapter 1658 and NFCSP funds and perform record keeping and data entry. Staff also received training on data collection and reporting, computer skills to expedite recording procedures, personnel issues.

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)

07/01/2002 through 06/30/2003

	Total	Bay Area CRC/FCA	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	16,379	3,331	1,219	2,301	1,568	1,746	1,404	725	584	1,576	716	1,209
Total # of family clients ^b receiving CRC core services	14,303	2,973	1,117	2,175	1,036	1,750	1,332	664	546	1,545	582	583
Avg. # of hours across ^c CRC core services (excluding respite)	4.4	3.3	3.8	3.9	2.3	3.1	4.9	6.4	6.0	8.1	5.4	4.0
Avg. # of hours across ^d CRC core services (including respite)	26.0	15.1	32.9	35.9	26.2	12.7	22.5	28.7	28.7	30.9	39.5	47.3

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 =14,303) 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
 07/01/2002 through 06/30/2003

Clients Receiving Program Services by Type of Service ^b	Total Clients Served	Average # of Clients Served ^c	Bay Area CRC/ FCA	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	7,581	689	1,551	489	1,248	791	660	672	316	211	633	274	736
Follow-up I&R	6,071	552	1,574	411	1,254	202	841	437	280	147	576	225	124
Assessment	3,939	358	672	309	506	389	440	456	139	217	477	137	197
Reassessment													
Full Reassessment	4,335	394	871	390	440	317	495	387	153	283	728	82	189
Status Change	4,065	407	1,120	373	351	545	0	359	134	227	445	230	281
Family Consultation	11,286	1,026	2,070	917	1,513	952	1,433	1,102	462	539	1,337	482	479
(Avg. number per month)	2,508	228	339	193	236	172	288	300	155	153	446	154	72
Counseling (Individual)	287	26	42	36	22	75	27	14	16	13	7	30	5
(Avg. number per month)	45	4	5	5	4	9	4	3	6	3	1	4	1
Legal/Financial Consult.	332	34	51	57	29	1	23	63	35	15	35	23	0
Psychoeducational Groups	349	39	116	17	53	0	0	44	9	27	59	17	7
Link2Care	706	71	145	35	87	39	72	141	0	59	43	38	47

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)
 07/01/2002 through 06/30/2003

Clients Receiving Program Services by Type of Service	Total Clients Served	Average # of Clients Served	Bay Area CRC/ FCA	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	1,712	156	180	157	274	91	172	136	67	135	286	122	92
Respite: Adult Day Care	209	19	9	28	14	6	35	14	7	16	34	34	12
Respite: In-home	1,430	130	111	123	263	77	146	122	58	131	244	82	73
Respite: 24-hour (out of home)	25	--	8	1	0	7	0	1	0	0	3	1	4
Respite: 24-hour (in-home)	76	--	41	15	0	1	1	0	3	0	10	1	4
Respite: Camp	16	--	15	0	0	1	0	0	0	0	0	0	0
Respite: Transport	7	--	0	0	0	0	0	0	0	0	4	2	1
Respite: Other ^f	82	--	7	0	0	1	0	0	0	0	31	30	13
Respite (Avg. number per month)	771	70	64	69	134	43	63	66	45	57	111	60	59
Respite Wait List	4,281	389	690	300	801	152	438	344	244	231	667	64	350
Caregiver Retreat	179	36	21	7	62	0	0	0	0	0	80	0	9
Support Groups (Avg. number per month)	901	82	17	97	53	77	34	175	85	88	160	73	42
	256	23	7	23	17	21	4	53	27	30	40	24	10

a 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.

b Includes group respite, provided on an hourly basis.

TABLE 3
 CAREGIVER RESOURCE CENTERS
 DIRECT SERVICE UTILIZATION
 07/01/2002 through 06/30/2003

Type of Service	Total Units of Service Provided ^a	Average # of Clients Served	Bay Area CRC/ FCA	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	7,581 clients served	689	1,551	489	1,248	791	660	672	316	211	633	274	736
Followup I&R ^c	4,613 hours	419	950	278	785	85	831	390	653	100	343	126	72
Assessment	3,946 assess. conducted	359	672	309	506	394	442	456	139	217	477	137	197
Reassessment													
Full Reassessment	5,518	502	1,139	476	490	378	599	467	198	344	1,090	100	237
Status Change	4,215	422	1,195	373	380	547	0	360	134	236	468	234	288
	reassess. conducted												
Family Consultation ^c	28,361 hours	2,578	3,333	2,679	2,417	1,598	3,262	3,290	2,030	1,807	5,237	1,319	1,389
Counseling (Individual) ^c	1,226 hours	111	190	193	99	162	76	49	179	53	24	162	39

a Average unites 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)
07/01/2002 through 06/30/2003

Type of Service	Total Units of Service Provided	Average # of Clients Served	Bay Area CRC/ FCA	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	402 hours	40	73	57	41	1	24	63	50	16	54	23	0
Psychoeducational Groups ^d	6,829 hours	759	4,132	154	864	0	0	531	116	241	620	151	20
Total Respite ^e	309,054 hours	28,096	35,097	32,547	69,559	24,719	16,312	23,350	14,807	12,404	35,333	19,833	25,093
Respite: Adult Day Care ^f	7,989 hours	726	964	1,051	579	323	917	478	349	421	1,123	1,357	427
Respite: In-home	227,420 hours	20,675	21,539	19,046	65,506	19,354	9,869	19,980	11,716	9,457	23,337	9,403	18,213
Respite: 24-hour ^g (out of home)	200 24 hr days	--	32	14	0	123	0	1	0	0	10	3	17
Respite: 24-hour (in home)	653 24 hr days	--	248	242	0	2	1	0	27	0	48	2	83
Respite: Camp ^d	102 24 hr days	--	30	0	0	72	0	0	0	0	0	0	0
Respite: Transportation	663 1-way trip	--	0	0	0	0	0	0	0	0	181	172	310
Respite: Other ^f	5,107 hours	--	60	0	0	32	0	0	0	0	2,743	811	1,461
Avg. # Months on Respite Wait List	N/A	23	18	17	13	60	59	8	23	11	14	7	23
Caregiver Retreat ^d	489 24 hr days		42	14	126	0	0	0	0	0	264	0	43
Support Groups ^d	8,108 hours	98	138	519	1,211	532	198	1,866	758	787	946	925	228

^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)

07/01/2002 through 06/30/2003

CRC Service Type	Average Hours ^a	Bay Area CRC/ FCA	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	0.6	0.7	0.6	0.4	1.0	0.9	2.3	0.7	0.6	0.6	0.6
Family Consultation	2.5	1.6	2.9	1.6	1.7	2.3	3.0	4.4	3.4	3.9	2.7	2.9
Counseling (Individual)	4.1	4.3	5.4	4.5	1.8	2.6	3.5	10.5	4.1	3.4	5.4	7.8
Legal/Financial Consult	4.3	1.4	1.0	1.4	1.0	1.0	1.0	1.4	1.1	1.5	1.0	0.0
Psychoeducational Groups	19.6	35.6	9.1	16.3	0.0	0.0	12.1	12.9	8.9	10.5	8.9	2.9
Respite Care	400.8 b	548.4	471.7	519.1	574.9	258.9	353.8	329.0	217.6	318.3	330.6	425.3
Support Groups	9.0	8.1	5.4	22.8	6.9	5.8	10.7	8.9	8.9	5.9	12.7	5.4

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 27 hours per month or 6 hours per week.

TABLE 5
 CAREGIVER RESOURCE CENTERS
 CASE STATUS SUMMARY
 07/01/2002 through 06/30/2003

	Total	Bay Area CRC/FCA	Redwood	Los Angeles	Inland	Del Oro	Southern	Coast	Mountain	Valley	Del Mar	Orange
Total Active Cases at Start of Report Period	9,695	862	620	1149	647	3531	698	289	365	841	374	319
# New Clients Added	3,974	682	310	511	397	443	456	139	217	477	142	200
# Client Reactivated ^a	324	226	12	1	0	3	32	3	3	5	12	27
Total Active Cases During Report Period ^b	13,993	1,770	942	1,661	1,044	3,977	1,186	431	585	1,323	528	546
# Cases Made Inactive	8	0	0	0	0	0	0	0	0	0	0	8
# Active Cases Closed	3,021	454	324	323	466	43	337	129	209	411	182	143
# Inactive Cases Closed	952	566	49	29	73	5	22	4	0	24	43	137
Reason closed												
--Caregiver died	61	8	4	15	2	0	7	1	4	7	7	6
--Caregiver moved	160	38	16	38	2	1	7	5	9	23	11	10
--Patient died	1,153	249	146	160	18	0	130	64	90	164	73	59
--Other ^c	2,241	705	338	173	20	164	212	106	100	147	97	179
# Patients placed in facilities ^c	564	106	51	67	3	17	53	68	67	119	8	5
--SNF	384	52	43	51	2	13	31	44	49	91	7	1
--Rehab	3	1	0	0	0	0	1	0	0	1	0	0
--Acute Hospital	3	2	0	0	0	0	1	0	0	0	0	0
--Board & Care	151	47	8	9	1	3	15	24	17	24	1	2
--Other	23	4	0	7	0	1	5	0	1	3	0	2
Total Active Cases at End of Report Period ^d	10,964	1,316	618	1,338	578	3,934	849	302	376	912	346	395

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.

TABLE 5b
 CAREGIVER RESOURCE CENTERS ^{abc}
 CAREGIVER ASSESSMENT RETURN RATES/CES-D SCORE
 07/01/2002 through 06/30/2003

	July – September 2002				October – December 2002				January – March 2003				April – June 2003				TOTAL			
CRC	Total Assessed	Questionnaires Returned	Avg. CES-D		Total Assessed	Questionnaires Returned	Avg. CES-D		Total Assessed	Questionnaires Returned	Avg. CES-D		Total Assessed	Questionnaires Returned	Avg. CES-D		Total Assessed	Questionnaires Returned	Avg. CES-D	
	#	#	%	Score	#	#	%	Score	#	#	%	Score	#	#	%	Score	#	#	%	Score
Bay Area/FCA	147	107	72%	20	165	118	71%	19	207	158	76%	19	153	88	57%	17	672	471	70%	19
Redwood	74	68	91%	17	84	62	73%	18	70	61	87%	18	81	67	82%	22	309	258	83%	19
Los Angeles	129	123	95%	18	121	108	89%	18	119	101	84%	16	137	126	91%	17	506	458	90%	17
Inland	133	92	69%	19	120	81	67%	22	94	60	63%	21	43	37	86%	20	390	270	69%	20
Del Oro	139	74	53%	19	112	65	58%	18	76	72	94%	11	114	109	95%	13	441	320	72%	15
Southern Coast	121	104	85%	19	93	82	88%	17	113	105	92%	16	129	125	96%	16	456	416	91%	17
Mountain Valley	47	29	61%	18	80	50	62%	19	61	54	88%	16	29	26	89%	19	217	159	73%	18
Del Mar	129	128	99%	17	105	105	100%	17	121	113	93%	16	122	119	97%	16	477	465	97%	17
Orange	31	29	93%	17	26	23	88%	19	31	31	100%	18	49	44	89%	17	137	127	92%	17
	51	49	96%	23	32	29	90%	20	55	52	92%	20	59	53	89%	18	197	183	92%	20
Total	1041	841	80%	19	972	755	77%	19	976	836	85%	17	952	830	87%	17	3941	3262	82%	18

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

b A revised assessment tool was implemented in January 1998; 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
07/01/2002 through 06/30/2003**

Expenditures ^a	Total \$	Bay Area CRC/FCA	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	\$2,434,753	\$225,244	\$221,829	\$650,975	\$166,443	\$154,668	\$210,945	\$128,915	\$132,540	\$250,544	\$123,644	\$169,006
(Avg. # per family client)	\$1,703	\$2,029	\$1,803	\$2,475	\$2,162	\$1,059	\$1,729	\$2,223	\$1,012	\$1,027	\$1,508	\$2,315
Adult Day Care Respite ^b	\$300,909	\$22,526	\$42,144	\$35,803	\$11,567	\$39,658	\$14,663	\$15,405	\$9,640	\$39,361	\$49,732	\$20,410
(Avg. # per family client)	\$1,440	\$2,503	\$1,505	\$2,557	\$1,928	\$1,133	\$1,047	\$2,201	\$603	\$1,158	\$1,463	\$1,701
24-hour In-Home Respite ^b	\$78,045	\$28,639	\$31,715	\$0	\$300	\$205	\$0	\$3,935	\$0	\$4,001	\$250	\$9,000
(Avg. # per family client)	\$1,027	\$699	\$2,114	\$0	\$300	\$205	\$0	\$1,312	\$0	\$400	\$250	\$2,250
24-hour Out-of-Home Respite ^b	\$27,388	\$4,468	\$2,100	\$0	\$16,364	\$0	\$1,456	\$0	\$0	\$1,110	\$390	\$1,500
(Avg. # per family client)	\$1,096	\$559	\$2,100	\$0	\$2,338	\$0	\$1,456	\$0	\$0	\$370	\$390	\$375
Respite Camp	\$12,010	\$11,434	\$0	\$0	\$576	\$0	\$0	\$0	\$0	\$0	\$0	\$0
(Avg. # per family client)	\$751	\$762	\$0	\$0	\$576	\$0	\$0	\$0	\$0	\$0	\$0	\$0
Other Respite ^b	\$44,102	\$1,786	\$0	\$0	\$320	\$0	\$0	\$0	\$0	\$9,690	\$17,199	\$15,107
(Avg. # per family client)	\$538	\$255	\$0	\$0	\$320	\$0	\$0	\$0	\$0	\$313	\$573	\$1,162
Legal Consultation	\$38,229	\$7,340	\$3,990	\$6,220	\$100	\$1,575	\$7,245	\$5,000	\$1,545	\$2,914	\$2,300	\$0
(Avg. # per family client)	\$115	\$144	\$70	\$214	\$100	\$68	\$115	\$143	\$103	\$83	\$100	\$0
Counseling (Individual) ^c	\$38,642	\$9,975	\$10,470	\$0	\$877	\$1,100	\$0	\$2,465	\$2,270	\$1,615	\$9,870	\$0
(Avg. # per family client)	\$276	\$475	\$291	\$0	\$42	\$183	\$0	\$411	\$175	\$231	\$329	\$0
Total	\$2,974,078	\$311,412	\$312,248	\$692,998	\$196,547	\$197,206	\$234,309	\$155,720	\$145,995	\$309,235	\$203,385	\$215,023

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 301 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
 07/01/2002 THROUGH 06/30/2003

Service	Average Cost per Client per Month	Average Cost per Client per Year
CRC Respite (Voucher)	\$332 ^a	\$3,758 ^b
Skilled Nursing Facility: Medi-Cal	\$3,423 ^c	\$41,511
Skilled Nursing Facility: Private Pay	\$4,415 ^d	\$52,980

- a Based on total expenditures and family client caseload figures for CRC respite voucher services for FY 2002-2003 (See table 9).Includes an average co-payment of \$19.
- b Assumes an average of seven hours of respite care per week for 12 months (See Table 9).
- c 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.)
- d Source: This 2003 estimate was taken reported by California Advocates for Nursing Home Reform (CANHR), http://www.canhr.org/medcal/EPRrates_2003.html.

TABLE 8
 CAREGIVER RESOURCE CENTERS
 HOURS OF RESPITE CARE PROVIDED
 07/01/2002 through 06/30/2003

Respite	Total	Bay Area CRC/ FCA	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	1,712	180	157	274	91	172	136	67	135	286	122	92
Average Monthly Respite Caseload	^a 771	64	69	134	43	63	66	45	57	111	60	59
Total Hours of Respite ^b	309,054	35,097	32,547	69,559	24,719	16,312	23,350	14,807	12,404	35,333	19,833	25,093
Average Number of Hours of Respite per Family Client	401	548	472	519	575	259	354	329	218	318	331	425
Average Number of Hours of Respite per Family Client per Month ^c	33	46	39	43	48	22	30	27	18	27	28	35
Average Number of Hours of Respite per Family Client per Week ^d	8	11	9	10	11	5	7	6	4	6	6	8

a Figure represents the total monthly caseload at all 11 CRCs statewide; the average monthly caseload across CRCs is 70 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
07/01/2002 through 06/30/2003**

Respite	Total	Bay Area CRC/FCA	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	\$3,169,300	\$322,914	\$338,453	\$ 727,458	\$212,392	\$215,693	\$245,065	\$177,718	\$153,575	\$337,962	\$213,833	\$224,237
Total Reimbursement (co-payment) by Family Clients ^b	\$271,794	\$28,817	\$40,665	\$40,680	\$16,823	\$21,162	\$18,001	\$29,463	\$11,395	\$33,256	\$22,618	\$8,914
Total CRC Respite Expenditure ^c	\$2,897,506	\$294,097	\$297,788	\$686,778	\$195,569	\$194,531	\$227,064	\$148,255	\$142,180	\$304,706	\$191,215	\$215,323
Total No. of Family Clients	1,712	180	157	274	91	172	136	67	135	286	122	92
Total # of Family Clients Contributing Co-payment ^d	1,188	102	117	220	88	117	108	65	64	181	87	39
Average Respite Caseload per Month ^e	771	64	69	134	43	63	66	45	57	111	60	59
Percent of Families Contributing a Co-payment	69%	57%	75%	80%	97%	68%	79%	97%	47%	63%	71%	42%
Average Annual CRC Costs per Family Client ^f	\$3,758	\$4,595	\$4,316	\$5,125	\$4,548	\$3,088	\$3,440	\$3,295	\$2,494	\$2,745	\$3,187	\$3,650
Average Annual Reimbursement (co-payment) per Family Client	\$229	\$283	\$348	\$185	\$191	\$181	\$167	\$453	\$178	\$184	\$260	\$229
Average Annual Cost per Family client	\$3,987	\$4,878	\$4,664	\$5,310	\$4,739	\$3,269	\$3,607	\$3,748	\$2,672	\$2,929	\$3,447	\$3,879
Average CRC Cost per Family Client per Month	\$313	\$383	\$360	\$427	\$379	\$257	\$287	\$275	\$208	\$229	\$266	\$304
Average Reimbursement (co- payment) per Family Client per Month	\$19	\$24	\$29	\$15	\$16	\$15	\$14	\$38	\$15	\$15	\$22	\$19
Average Cost per Family Client per Month	\$332	\$407	\$389	\$442	\$395	\$272	\$301	\$313	\$223	\$244	\$288	\$323

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

b Includes share of cost for families using "direct pay" respite.

c Total CRC respite expenditure includes some funds generated from client co-payments which are used to augment CRC respite budgets.

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

e Calculated based on the total number of family clients served divided by the number of months in the report period.

f Calculated based on the average respite caseload per month.

TABLE 10
 CAREGIVER RESOURCE CENTERS
 EDUCATION AND TRAINING FACILITIES
 07/01/2002 through 06/30/2003

Education/Training Activity Type	Total CRCs ^a	Bay Area CRC/ FCA	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	15,974	2,824	632	3,958	5	3,778	2,746	170	291	598	406	566
OTHER EDUCATION/TRAINING EVENTS												
2. Total number of persons attending	4,839	935	80	889	0	609	1,150	68	350	667	10	81
ORIENTATION TO CRC SERVICES												
3. Total number of persons attending	10,706	385	296	952	5	1,958	2,667	46	191	3,242	964	0
Total	31,519	4,144	1,008	5,799	10	6,345	6,563	284	832	4,507	1,380	647

a Duplicated Count

TABLE 11
 CAREGIVER RESOURCE CENTERS
 TOP TEN UNMET NEEDS/SERVICE GAPS IDENTIFIED
 BY CRCS IN THEIR SERVICE REGIONS
 07/01/2002 through 06/30/2003

NEEDS IDENTIFIED	# OF CRCS REPORTING
Respite Services	6
Day/Community TBI Programs	5
Support Group	5
Bilingual Services	5
Assisted Living/Residential Care (affordable)	4
Transportation	4
Case Management Services for TBI	3
Emergency/General Psychiatric Services	3
Adult Day Care (brain injury)	3
Respite Care (affordability/funding)	2

TABLE 12
 CAREGIVER RESOURCE CENTERS
 MAJOR NEEDS/INFORMATION REQUESTED BY
 FAMILIES/CAREGIVERS AT CRC INTAKE ^a
 07/01/2002 through 06/30/2003

NEEDS IDENTIFIED	# REPORTING	% REPORTING ^b	RANK
General Information/Orientation to Brain Impairments	5382	71%	1
Respite Care (for the caregiver) ^c	4893	65%	2
Emotional Support	4788	63%	3
Direct Care of the Adult With Brain Impairment ^d	2886	38%	4
Financial Advice/Aid	2231	29%	5
Behavior Management Advice	1565	21%	6
Legal Information/Advice	1273	17%	7
Other	1212	16%	8
Placement Help	823	11%	9
Diagnostic/Medical Advice	406	5%	10
Rehabilitation	65	1%	11
Public Policy/Research	14	0%	12

a Needs identified are based on responses from 7,581 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
 07/01/2001 through 06/30/2002

NEEDS IDENTIFIED	# REPORTING	% REPORTING ^b	RANK
General Information/Orientation to Brain Impairments	486	44%	1
Emotional Support	317	29%	2
Respite Care (for the caregiver)	203	18%	3
Other	130	12%	4
Direct Care of the Adult with Brain Impairment	120	11%	5
Placement Help	71	6%	6
Legal Information/Advice	59	5%	7
Financial Advice/Aid	53	5%	8
Behavior Management Advice	33	3%	9
Public Policy/Research	14	1%	10
Training	13	1%	11
Diagnostic/Medical advice	10	1%	12
Rehabilitation	1	0%	13

a Needs identified are based on responses from 1,102 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 2002-2003

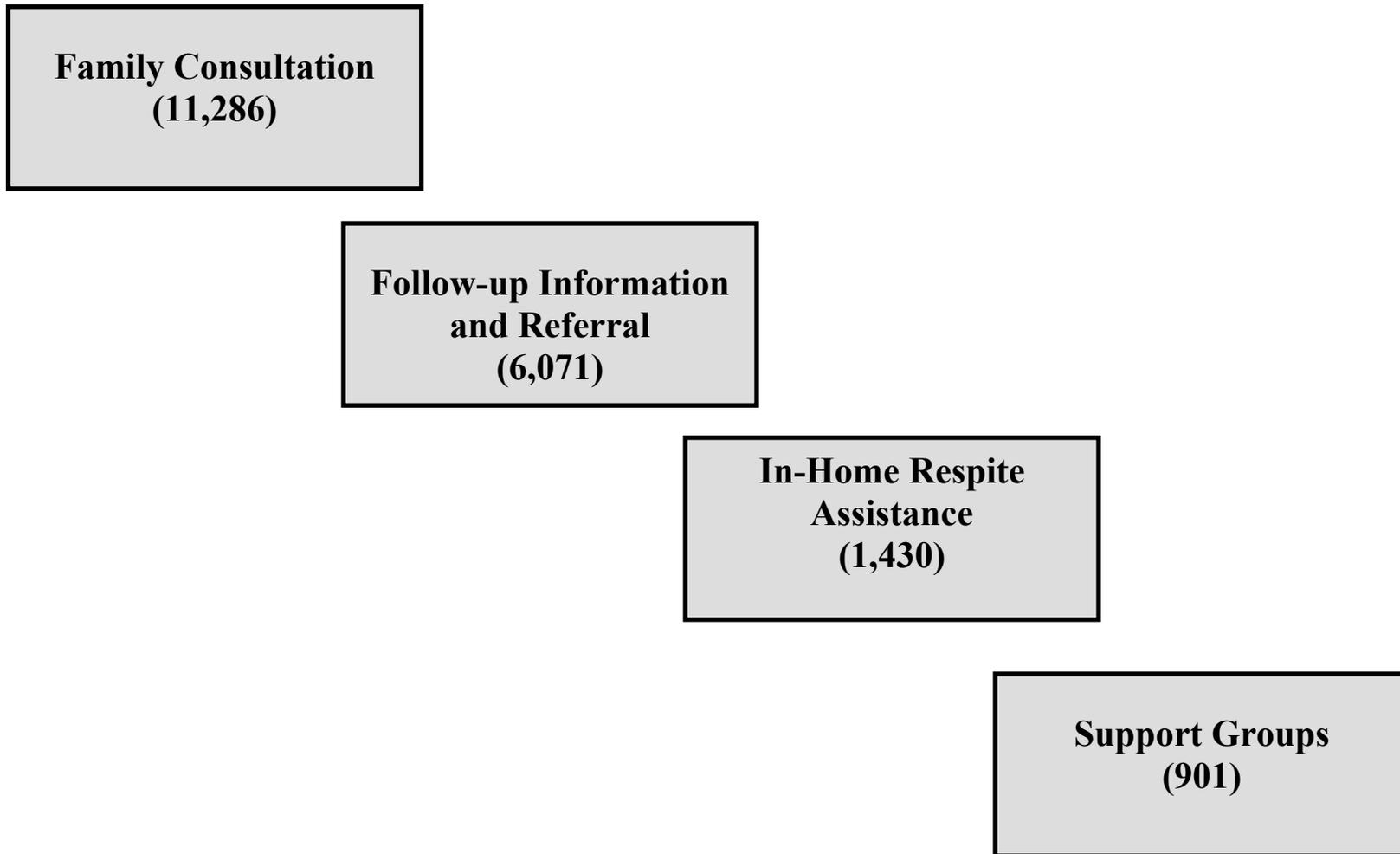
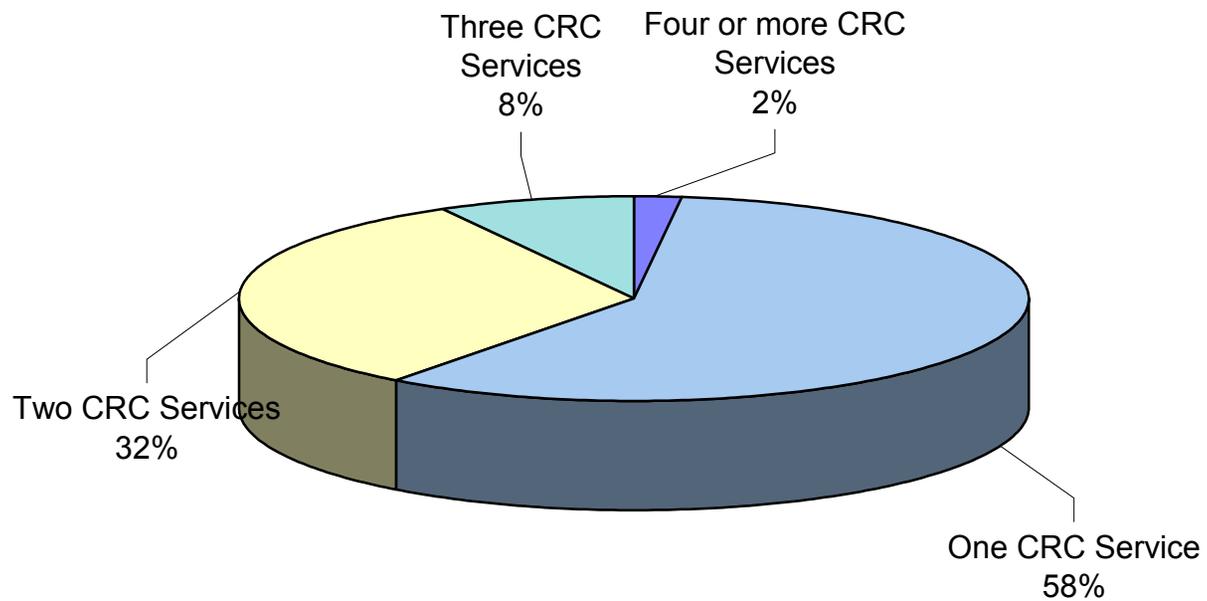


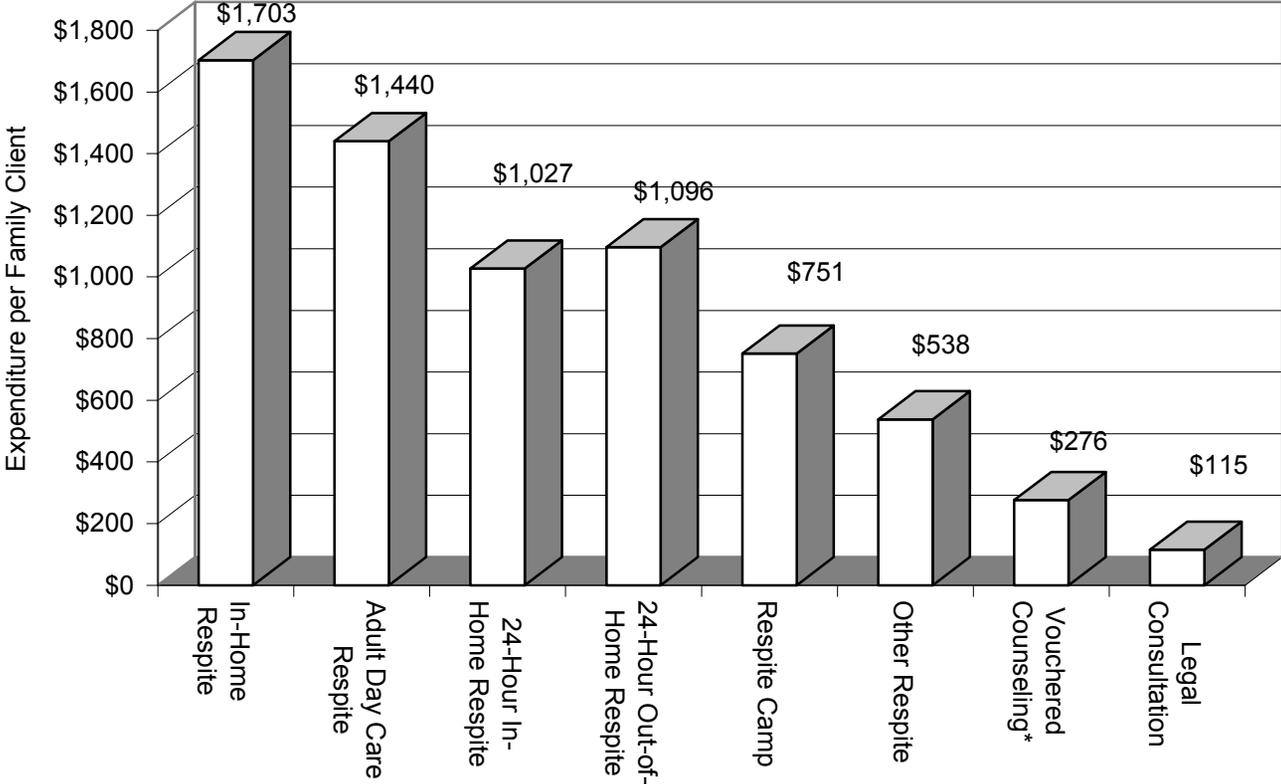
FIGURE 2
CAREGIVER RESOURCE CENTERS
THE PROPORTION OF FAMILY CAREGIVERS RECEIVING ONE,
TWO, THREE, OR FOUR PLUS SERVICES ^A
FY 2002-2003



N = 15,131

^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).

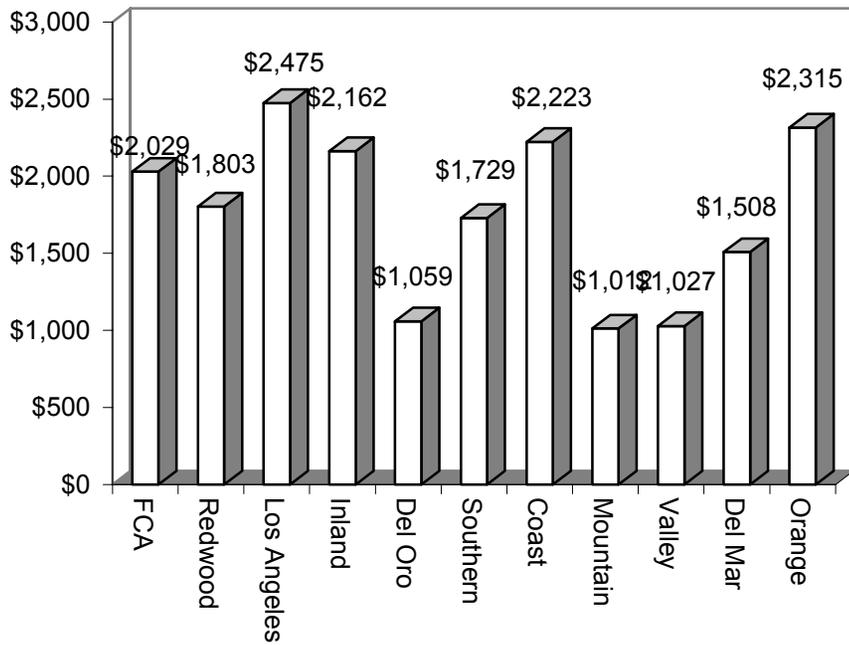
**FIGURE 3
 CAREGIVER RESOURCE CENTERS
 AVERAGE COST PER YEAR PER FAMILY CLIENT FOR
 CRC VOUCHER SERVICES, FY 2002-2003**



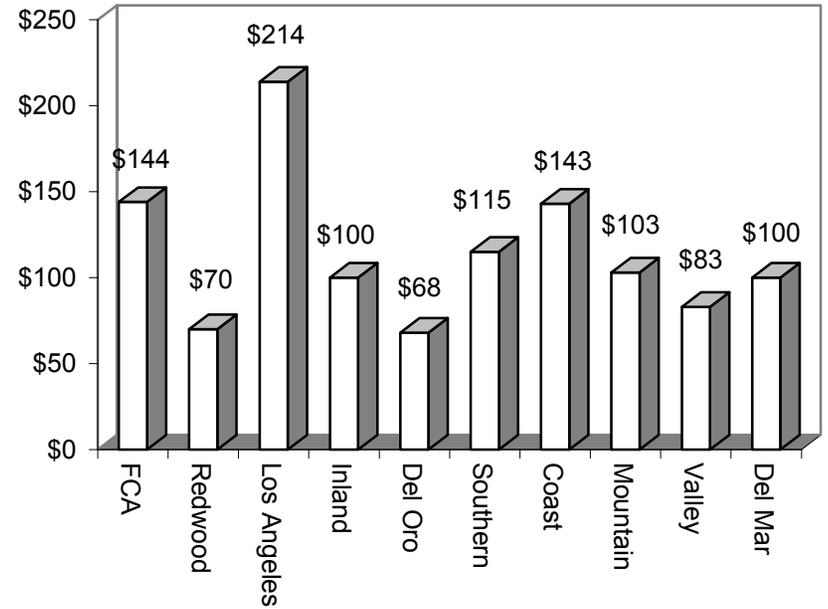
*Excludes counseling provided by salaried CRC staff.

**FIGURE 4
 CAREGIVER RESOURCE CENTERS
 ANNUAL COST PER FAMILY CLIENT BY CRC SITE:
 IN-HOME RESPITE AND LEGAL CONSULTATIONS
 FY 2002-2003**

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
RESPIRE CARE BY CRC SITE – TOTAL NUMBER OF FAMILY CLIENTS
SERVED IN FY 2001-2002 AND FY 2002-2003

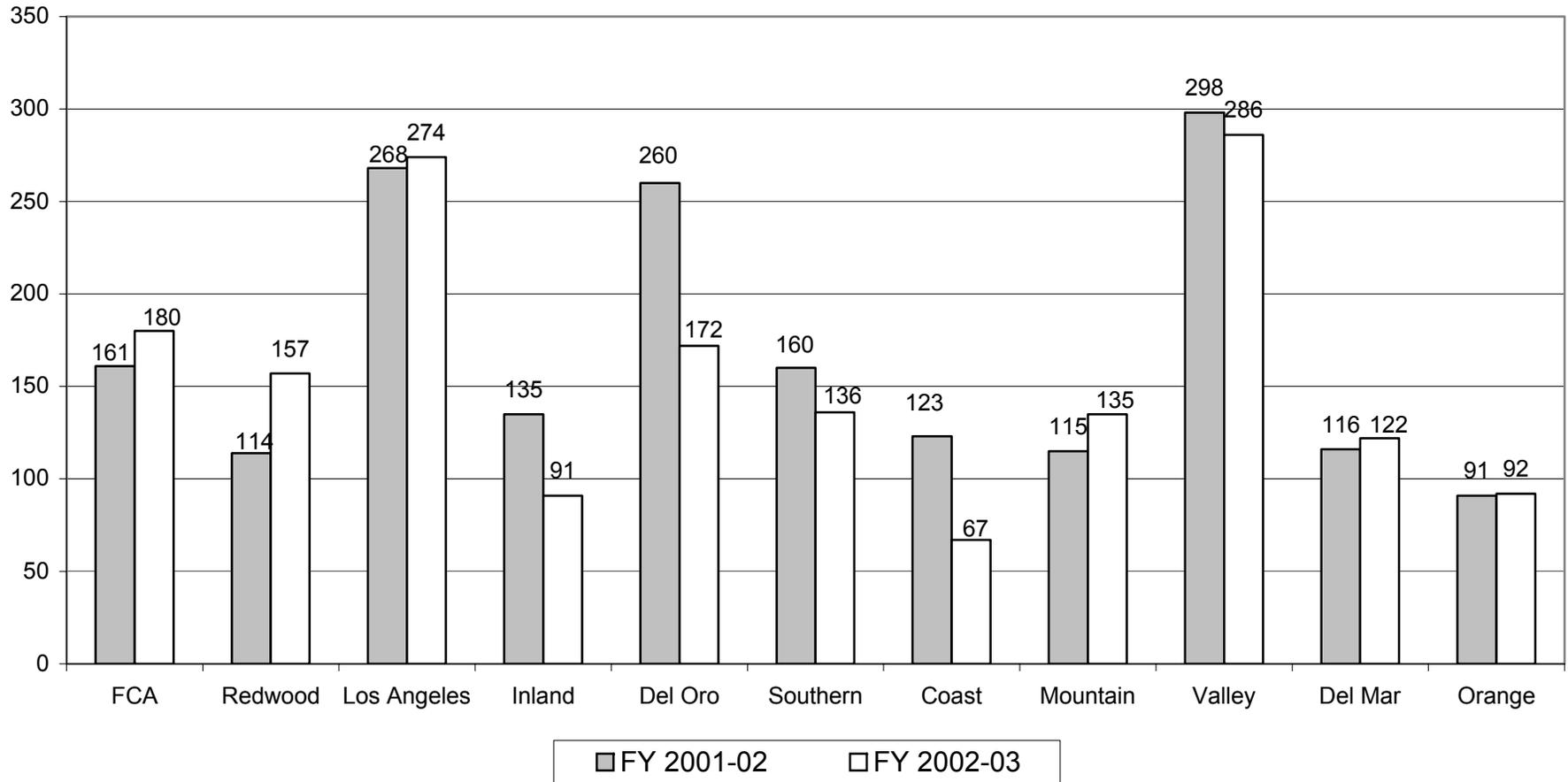
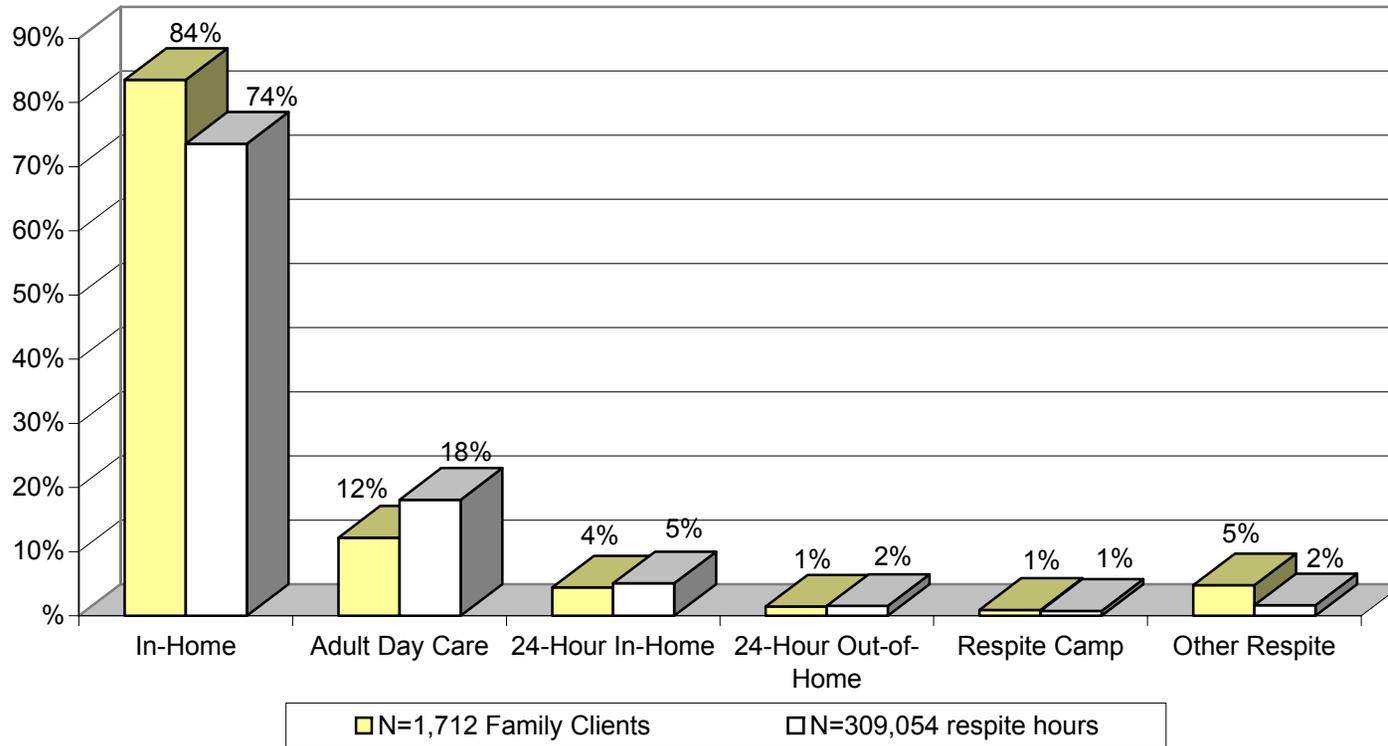
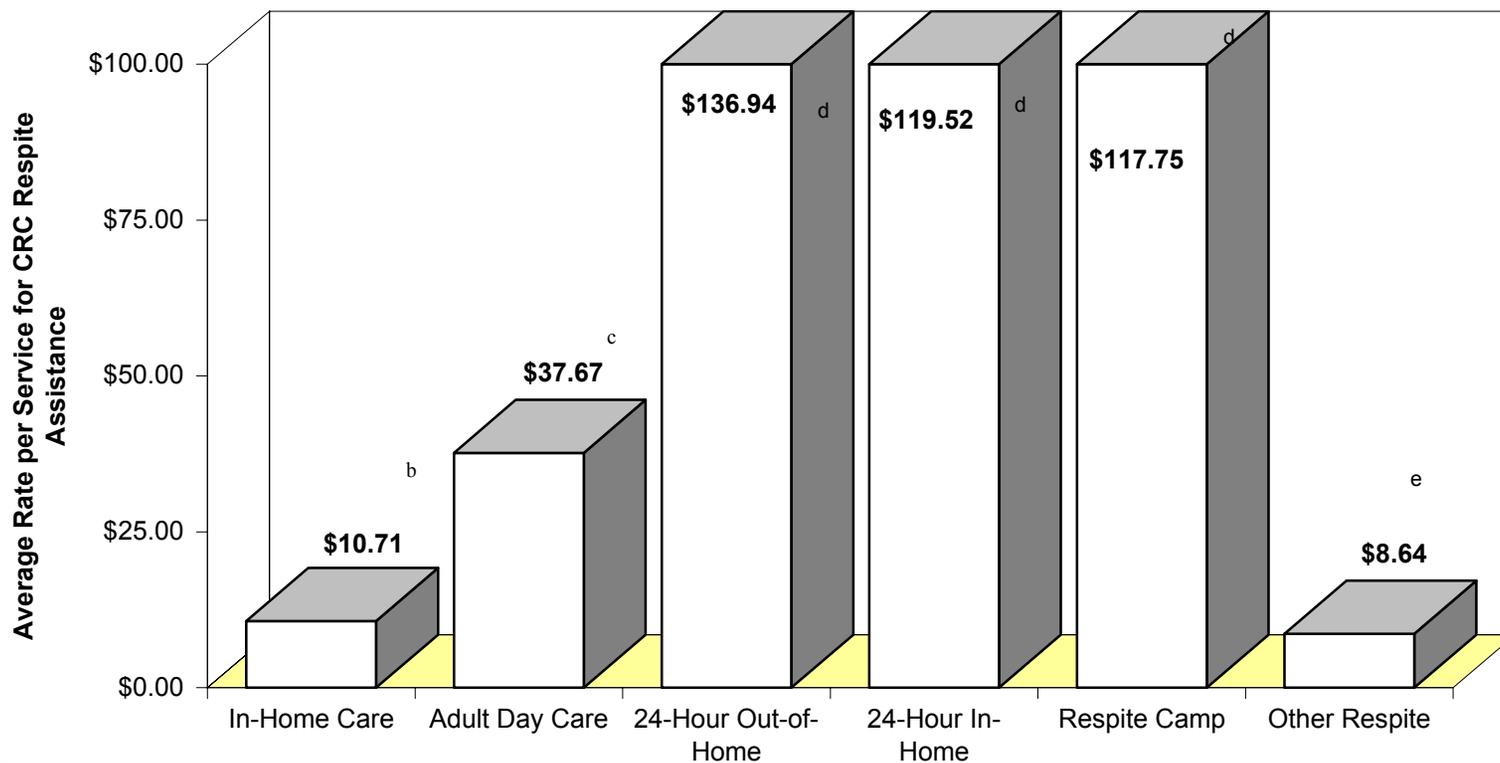


FIGURE 6
CAREGIVER RESOURCE CENTERS
CRC RESPITE USE BY TYPE OF RESPITE:
PROPORTION OF CLIENTS SERVED AND PROPORTION OF HOURS UTILIZED
FY 2002-2003



**FIGURE 7
CAREGIVER RESOURCE CENTERS
RESPIRE CARE: AVERAGE RATE PER SERVICE ^a
FY 2002-2003**



^a Excludes client co-payments.

^b Per hour.

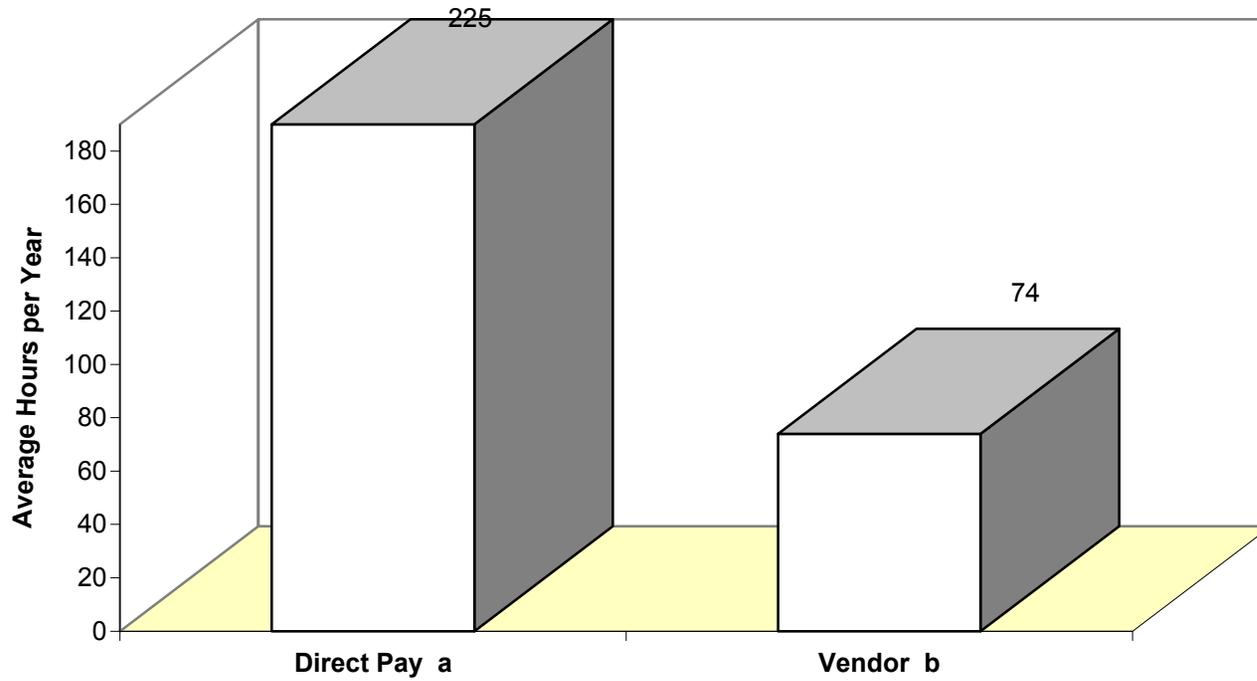
^c Per 7-hour day

^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 2002-2003

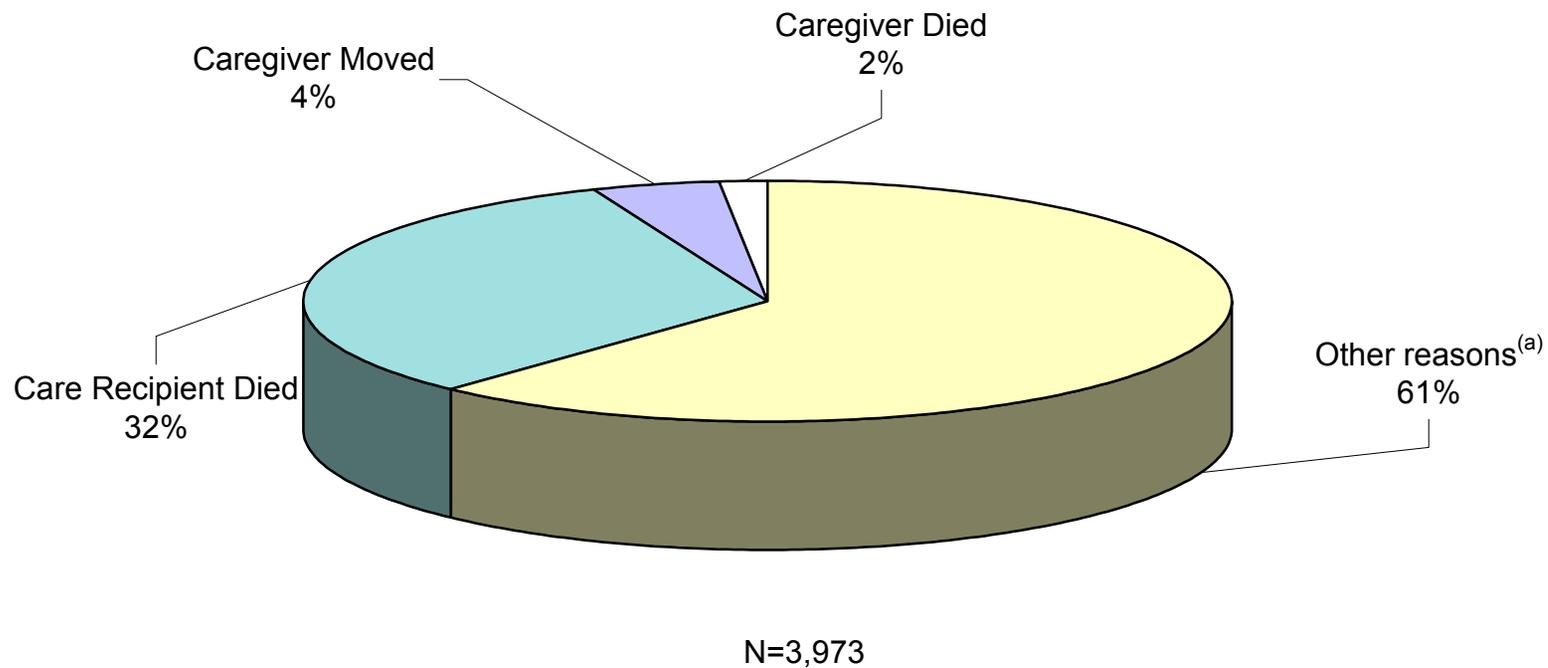


^a Based on 177,870 hours divided by 790 direct pay respite (in-home) clients.

^b Based on 49,517 hours divided by 667 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 2002-2003



^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 2002-2003

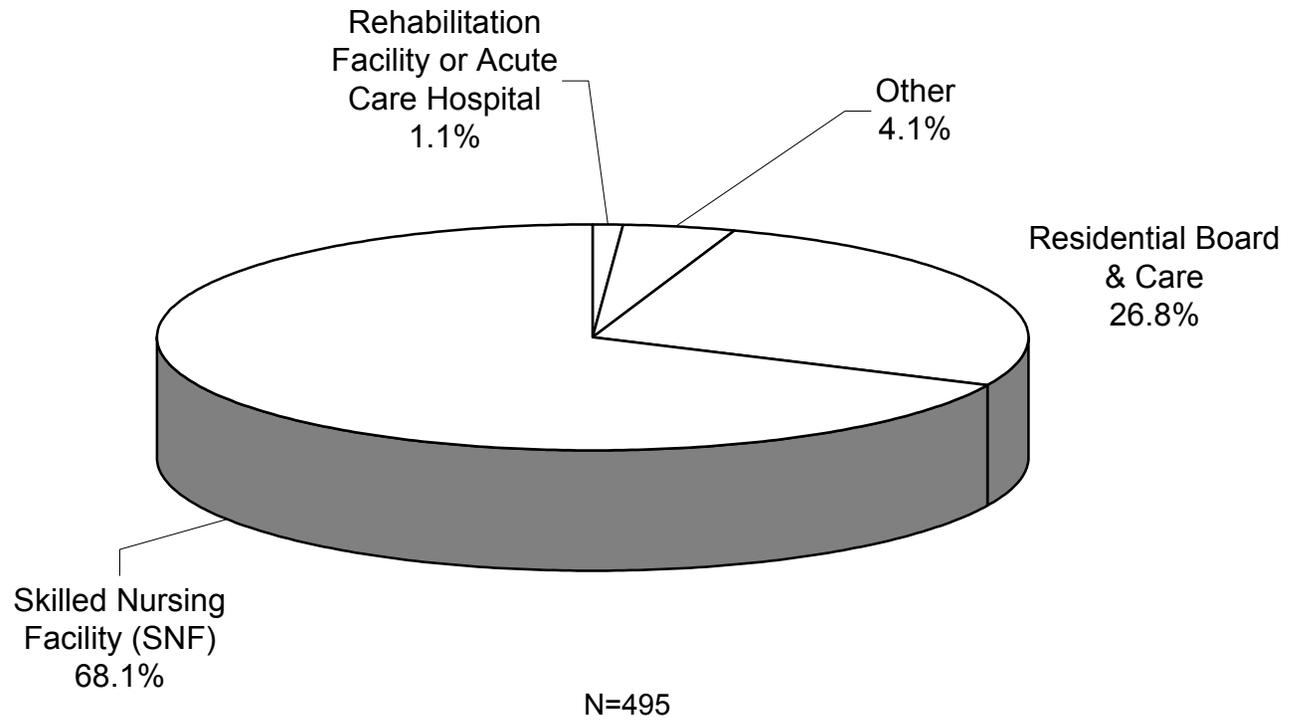
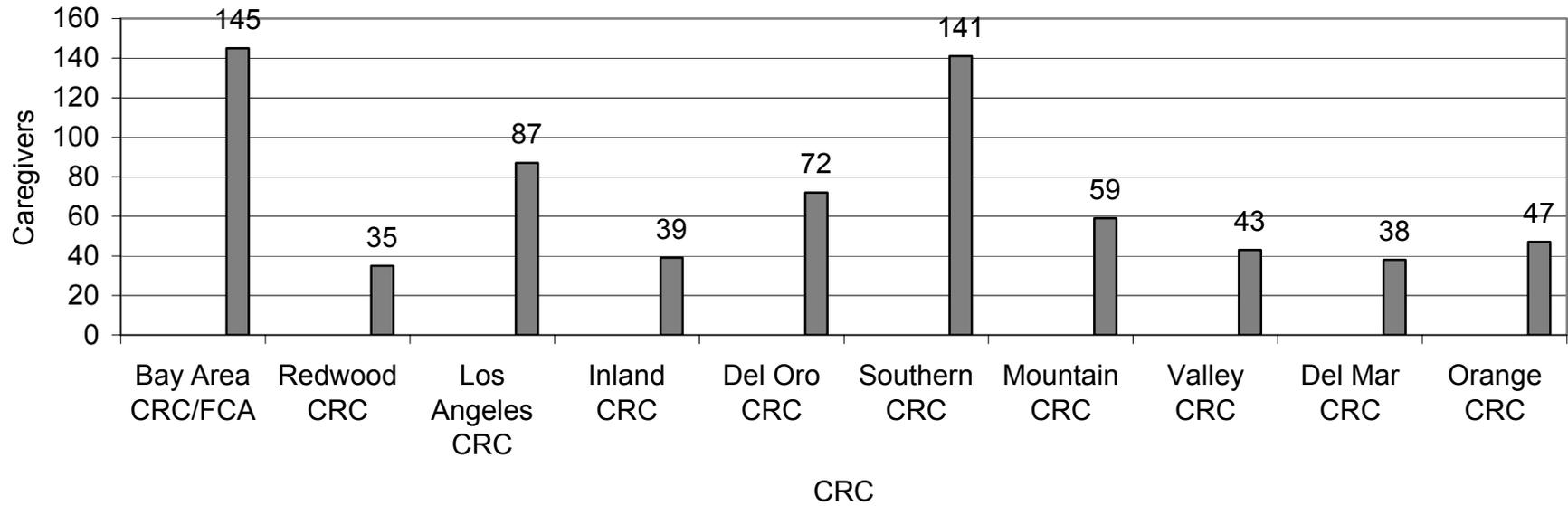


FIGURE 11
CAREGIVER RESOURCE CENTERS
LINK 2 CARE
ACTIVE CAREGIVER ENROLLMENT BY CRC
SEPTEMBER 2003



CALIFORNIA'S CAREGIVER RESOURCE CENTERS SITE DISTRIBUTION LIST

Site Number, CRC, and Counties Served	Host Agency	Program Information
<p>(01) BAY AREA CRC/FCA</p> <p>Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara</p>	<p>Family Caregiver Alliance Kathleen Kelly Executive Director 690 Market St., Suite 600 San Francisco, CA 94104 (415) 434-3388 (800) 445-8106 E-Mail: kkelly@caregiver.org</p>	<p>Donna Shempp Director, Programs and Services 690 Market St., Suite 600 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) 740-5904 (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	Arlene Hostetter 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: ahostetter@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

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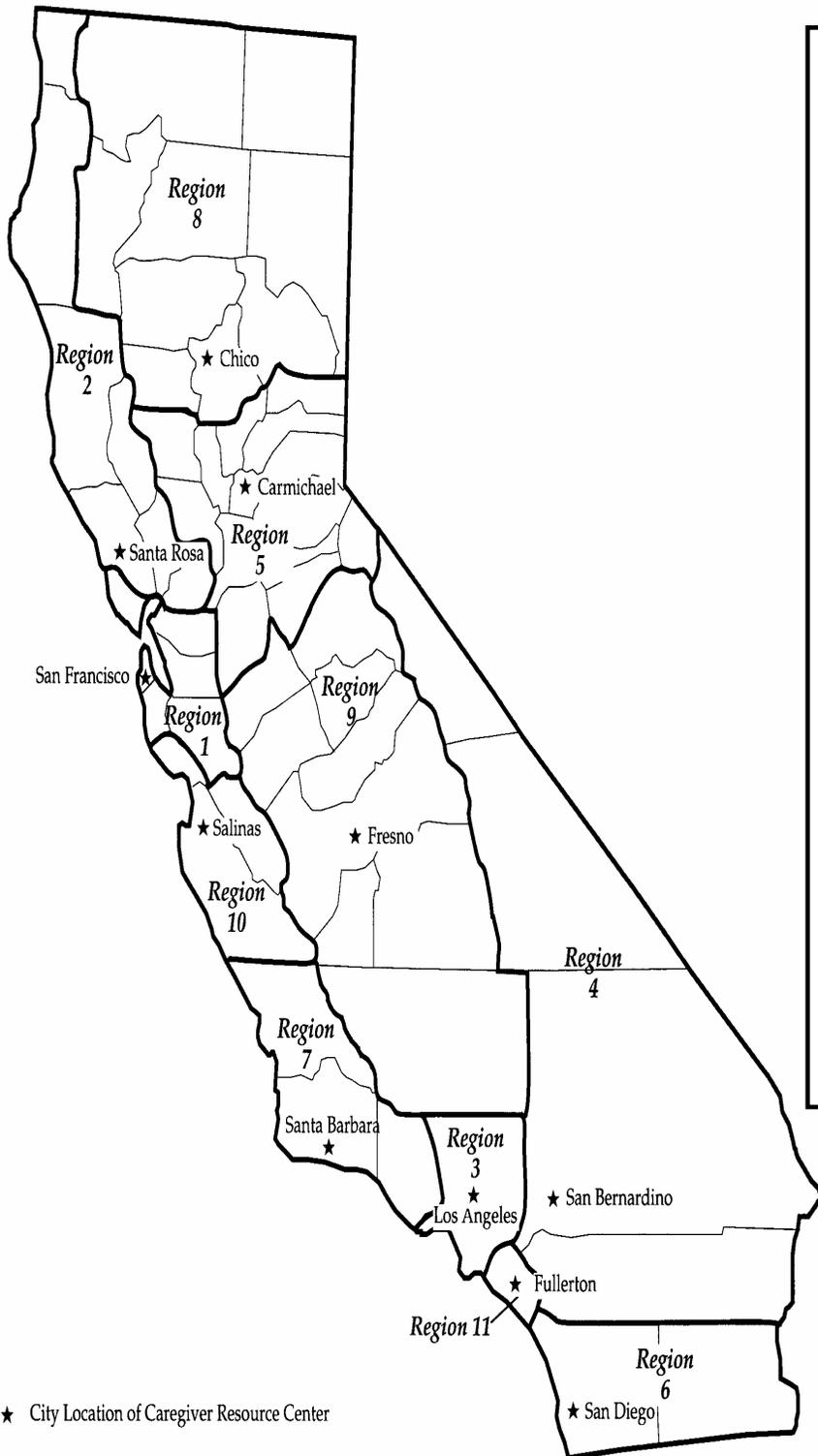
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MAP OF CALIFORNIA'S CAREGIVER RESOURCE CENTERS



★ 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 whom 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.