

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, 2004 through June 30, 2005

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Consultant at Family Caregiver Alliance in cooperation with
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Submitted by:
Statewide Resources Consultant
Family Caregiver Alliance
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434-3388
Email: info@caregiver.org
Web: www.caregiver.org

(415) 434-3388
(800) 445-8106

TABLE OF CONTENTS

EXECUTIVE SUMMARY.....	5
BACKGROUND AND HISTORY.....	10
METHODOLOGY.....	11
COST AND AMOUNT OF SERVICE PROVIDED.....	12
SERVICE DEMAND AND SUCCESS IN MEETING DEMAND.....	17
PROGRAM IMPACT.....	24
CRC SYSTEM STRATEGIC PLAN AND ACHIEVEMENTS.....	25
RECOMMENDATIONS.....	30
DATA TABLES.....	32

LIST OF TABLES

<u>TABLE</u>		<u>PAGE</u>
1	Total Clients Served and Average Hours of Service per Client	32
2	Client Status Summary (Caseload Activity)	33
3	Services Summary: Number of Clients Receiving Each Service	34
4	Units of Services Delivered	36
5	Amount of Service per Client by Service Type	38
6	Depression and Health Indices	39
7	Respite Care: Number Served and Hours per Year, Month, and Week	40
8	Respite Voucher Service Costs	41
9	Expenditures for All Voucher Services	42
10	Education and Training Activities	43
11	Unmet Needs and Service Gaps	44
12	Major Needs: Information Requested by Families and Caregivers at CRC Intake	45
13	Major Needs: Information Requested by Providers and General Public at CRC Intake	46
14	Comparison of CRC Respite Voucher Costs and SNF Costs	47

LIST OF FIGURES

<u>FIGURE</u>		<u>PAGE</u>
1	Percent of Closed Cases by Reason	15
2	Percent of Caregivers Receiving Services	16

EXECUTIVE SUMMARY

The year 2004 marked the 20th anniversary of California's Caregiver Resource Center (CRC) system. The CRC system was created by the *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults* and operates under the direction of the California Department of Mental Health (DMH).¹ In addition to developing CRCs to provide a single-entry network for caregivers, the law established a Statewide Resources Consultant (SRC). The SRC operates a statewide information and technical assistance clearinghouse on cognitive impairment and assists DMH by providing consultation, training, research, technical, and program assistance to the CRCs. As specified by the enabling legislation, the CRC system focuses on families whose loved ones are suffering from Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury (TBI), and other chronic or degenerative cognitive disorders that affect adults.² Over the past two decades, the 11 CRCs have supplied information, education, respite, and emotional support to more than 250,000 California families, helping them give long-term care at home.

Caregivers' lives change forever when their loved ones fall ill. Families, with tremendous dedication, are providing care at home as long as they can, as an alternative to institutionalization of their loved ones. The CRCs sustain family caregivers in roles that may be rewarding yet often entail great physical, emotional, and financial sacrifice.

This annual report includes information on all of the CRCs for the period from July 1, 2004, to June 30, 2005 (FY 2004-05). It provides a snapshot of California's family caregivers, the adults for whom they care, the services they use, the costs involved, and the challenges yet unmet. Thus, it addresses the enabling legislation's requirements to report annually to the Legislature:

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 the CRCs success in meeting this demand;
3. An analysis of the CRC system's success in: deterring the institutionalization of adults with brain impairments; allowing caregivers to maintain a more normal routine; and promoting the continuance of quality care for adults with cognitive impairment; and
4. Recommendations for ensuring that unmet needs of cognitive-impaired persons and their families are identified and addressed with appropriate programs and services.

The total contract awarded in FY 2004-05 to the 11 CRCs and the SRC was \$11,747,000, which is an amount that has remained unchanged for the past three years.

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 The term "family" is used inclusively in this report to refer both to relatives and to close friends engaged in caring for adults suffering from chronic, debilitating health conditions.

During FY 2004-05, some CRCs also received funding from the National Family Caregiver Support Program (NFCSP) administered through California's Department of Aging and 33 Area Agencies on Aging (AAAs). With NFCSP funds, the CRCs helped a broader range of caregivers gain access to: additional supportive services; information about available services; individual counseling; organization of support groups; caregiving training; respite care providing temporary relief from caregiving responsibilities; and supplemental services to complement their care efforts.³

CRC system highlights for the last year include:

- 6,988 new clients completed the intake process; the vast majority (83 percent) received follow-up information and referral; more than half of those completing intake (55 percent) were then assessed systematically for CRC services;
- 12,408 family caregivers were part of the CRCs' active caseload ("active" cases include only caregivers who have had an assessment after intake); fewer cases were closed due to out-of-home placement than in the previous two years—531 in FY 2004-05 versus 630 in FY 2003-04 and 564 in FY 2002-03;
- 11,859 clients received family consultations and 7,893 clients had reassessments;
- 17,292 individuals received one or more CRC services (as compared to 16,562 in FY 2003-04 and 16,379 in FY 2002-03); the number of families receiving CRC respite assistance in FY 2004-05 was 1,747;
- Family caregivers, on average, received significantly more hours of caregiver support services (not including respite) than in the previous two years (7.3 hours per caregiver in FY 2004-05, as compared to 5.7 hours in 2003-2004 and 4.4 hours in 2002-03);⁴
- the 11 CRCs expended \$2,517,265 for respite care voucher services; annualized, the average cost per family using respite care was \$1,441;⁵ and

³ Note that this report provides service information for Chapter 1658 funds and does not include detailed service data related to NFCSP funds.

⁴ Includes one or more of the following: family consultation, counseling, legal assistance, support group, caregiver retreat, education/training, and psychoeducational group.

⁵ In contrast, the average monthly cost for a Medi-Cal patient in a California skilled nursing facility (SNF) was \$3,797 in FY 2004-05 and the average monthly private pay rate in a California nursing home was \$4,477 in 2004. (Data from California Department of Health Services, Medi-Cal Policy Division, Rate Development Branch, Long-Term Care Reimbursement Unit, personal communication, 10/17/05; and California Advocates for Nursing Home Reform (CANHR). "CANHR Fact Sheets: How to Choose a Nursing Home." www.canhr.org/publications/factsheets/fs_howtochoose.htm.)

- The average client wait-time for CRC respite assistance increased by four months to a 29-month wait; at the end of FY 2004-05, 5,159 family caregivers were on respite waiting lists at CRCs in California.

CRC statewide assessment data shows that for FY 2004-05:⁶

- The typical family caregiver being served by the CRC system is 58 years old and cares for someone who is 74. Many caregivers (43 percent) are age 60 or older; 26 percent are between the ages of 36 and 50; and 16 percent are age 75 or older. While the average age of caregivers has declined a little over the last 15 years (from age 61 in 1990 to age 58 in FY 2004-05), the age of care recipients has increased steadily (from age 70 in 1990 to age 74 in FY 2004-05).
- Caregivers seeking assistance are increasingly diverse ethnically. The non-White proportion of CRC clients has grown to 32 percent in FY 2004-05—14 percent are Hispanic, 9 percent are African American, 6 percent are Asian/Pacific Islander, and 3 percent identified as “Other.” By comparison, the proportion of non-White caregivers served by the CRC system in 1990 was 12 percent.
- The family caregiver is most frequently a female (77 percent), and she is often the daughter (37 percent) or wife (24 percent) of the care recipient. Also, more care recipients are female (56 percent).
- Nearly half (47 percent) of caregivers under the age of 65 work either full time (33 percent) or part time (14 percent).
- Nearly two-thirds (63 percent) of care receivers are unable to manage three to five of their own daily living activities (such as bathing, eating, and dressing); more than three quarters (79 percent) cannot be left alone and more than half (56 percent) are incontinent.
- The caregiver’s average tenure in the caregiving role was 3.8 years. The range of time spent as a caregiver is vast, with some caregivers having begun less than a year ago and one caregiver reporting providing care for 60 years.
- Caregivers provide an average of 12.2 hours of care per day, seven days per week—much more than a full-time job.
- Caregivers receive an average of only 1.2 hours of help per day from family members or friends. One in five (20 percent) said they get no help. Another 58 percent reported that they receive “far less” or “somewhat less” help than they need from family or friends.

⁶ Data are from the CRC Intake data set and the Uniform Assessment Database FY2004-2005. See the Methodology section for more detailed information.

- More than half (56 percent) of caregivers reported feeling “depressed” or “anxious.” Based on standard measures, 43 percent are depressed and 50 percent have high burden levels.

At the time of first contact with the CRCs, the most frequently expressed need among caregivers was the need for general information, followed by emotional support, and respite. For caregivers who have been assessed and are clients of the CRC system, **respite care was the most frequently identified unmet need, followed by emotional support, and basic information.** In some difficult cases, it may not be possible for family caregivers to keep their loved ones at home. However, information and support services from the CRCs clearly help to deter the institutionalization of the care receiver.

The following are recommendations to 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, widely disseminated information and education campaigns target 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.
3. Promote policies that recognize and assess family caregivers as part of transitional (hospital/SNF to home) and long-term care planning.
4. Utilize the CRC Uniform Client Record System to monitor and promote targeted outcomes for caregivers.
5. Improve assistance to working and isolated caregivers via technology. For example, increase the number of caregivers using the Internet-based Link2Care program.
6. Explore the idea of establishing liaisons with the private sector to provide caregiving resources to caregivers who work outside the home.
7. Work cohesively with statewide groups addressing the need for appropriate and affordable long-term care options. Improve the situations of care receivers and their family caregivers through public awareness and the development of affordable, accessible, and culturally appropriate long-term care services.
8. Identify viable program options for traumatic brain injury caregivers and their loved ones.
9. Carry out CRC research to: (1) measure and analyze the impact of cognitive disorders on family and caregiver well being; (2) coordinate outcome measures

with recommended interventions to refine core CRC services to family caregivers; and (3) evaluate new modes of communication, support, and education for caregiver families.

10. Enhance local partnerships with AAAs to expand family consultations, counseling, and respite services to caregivers using National Family Caregiver Support Program funds.

BACKGROUND AND HISTORY

When an adult in California suffers from chronic, debilitating health conditions, dedicated families—not institutions—provide most of the care. The demand for and number of informal caregivers—those who provide care without pay—increases as California’s population grows larger and older. One in every six California households includes at least one caregiver for someone age 50 or over.⁷ Caregivers of cognitively impaired adults have special needs beyond the basic information, emotional support, and occasional respite from ongoing demands that any caregiver would want. Alzheimer’s disease, stroke, Parkinson’s disease, Huntington’s disease, and traumatic brain injury all cause cognitive, behavioral, and psychological changes that affect memory, emotional well being, and the ability to do ordinary daily activities such as bathing, eating, and dressing.

The caregiver has a stressful, demanding role—even though it may be rewarding. Along with the loved one’s memory loss, behavioral and personality changes, the caregiver faces round-the-clock care needs and high care costs. At risk are the caregiver’s physical and mental health, the family’s emotional and economic well being, and the loved one’s ability to continue living in the home.

The California State Legislature enacted the *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults*, Chapter 1658, Statutes of 1984, to address the needs of adults with brain impairments—a population traditionally outside the mainstream service delivery system. The act marked a triumph for a grassroots community effort begun in San Francisco in 1976. It built upon a needs assessment and pilot program conducted by Family Caregiver Alliance that showed the effectiveness of services to families and caregivers of adults with cognitive impairment.

This legislation, as amended by Chapter 775, 1988, and Chapter 7, W&I Code, Section 4362 et al., 1992, created statewide support services for family caregivers. The Department of Mental Health (DMH) established a statewide system of Caregiver Resource Centers (CRCs) in California. The 11 CRCs facilitate a single point of entry for caregivers within their respective service regions. As also provided by the law, a Statewide Resources Consultant (SRC) serves as the centralized information and technical assistance clearinghouse on caregiving and cognitive impairment; provides consultation, training, and technical assistance to the CRCs; conducts conferences, social policy research, and training programs to enhance the quality of care and treatment of adults with brain impairments; assists the state in coordinating with other state initiatives; and aids DMH in evaluating the effectiveness of the CRC system.

DMH, in consultation with the SRC, is required to report annually to the Legislature. Reports are to include:

⁷ 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*. From http://cssr.berkeley.edu/aging/pdfs/FamCareProfile_Entire.pdf

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 CRC success in meeting this demand;
3. An analysis of the program's efforts to: deter the institutionalization of adults with brain impairments; allow caregivers to maintain a more normal routine; and promote the continuance of quality care for adults with cognitive impairment; and
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 11 CRCs for the period July 1, 2004, through June 30, 2005.

METHODOLOGY

Five sources of information have been used for this report: (1) the CRC Services Automation System, through which quarterly data are collected on caregivers, care receivers, services and expenditures; (2) the CRC Semiannual Progress Reports; (3) CRC uniform caregiver assessment data; (4) the Quarterly Calendar of Workshops and Classes; and (5) the CRC 2004 Satisfaction Survey.

1. ***CRC Services Automation System (and Caller/Caregiver Provider Tracking System)*** collects data on all clients served, including date of service, service mix, and case status. These data are transmitted to the SRC electronically each quarter. Major data components used in this report include:
 - a. Data on individuals completing the CRC intake process (for example, the total number of callers, callers' reported ethnicity, and a summary of callers' identified needs);
 - b. Number of family caregivers served and average service mix;
 - c. Units of each service provided to family caregivers;
 - d. Expenditures for voucher services; and
 - e. Co-payments for respite services paid by family caregivers.
2. ***Semiannual Progress Reports***, submitted by each CRC to the SRC and DMH, cover CRC progress on staffing and administrative functions, document new unmet needs in the region, and report activities and accomplishments. Information about unmet needs and progress on the strategic plan is used in this report.
3. ***Uniform Caregiver Assessment Tool*** data describe family caregivers who seek any type of help (in addition to basic information) from the CRCs. CRC service staff collect the data using a comprehensive assessment instrument. Each CRC submits a hard copy of its completed instruments to the SRC for entry into the

database. Data components included in this report include:

- a. Demographic information for caregivers and care receivers (such as marital status and income);
 - b. Caregiver characteristics (such as work status, health, level of burden, depression score, relationship to care receiver, hours per week of caregiving, and hours of unpaid help received weekly from others); and
 - c. Care receiver characteristics (such as behavioral and functional problems).
4. *Quarterly Calendar of Workshops and Classes*, the statewide listing for all CRC educational events, is compiled by the SRC from submissions provided by the CRCs. It includes the title, date, and sponsorship of each class or event. Information on the types and number of sessions held by each CRC is used in this report.
5. *CRC 2004 Satisfaction Survey*, conducted by the SRC, collected data from a computer-generated sample of caregivers served by all CRCs between January and March 2004. Of the 4,311 caregivers selected to complete the survey, 1,355 responded—a 31 percent response rate. Respondents provided information about the length of time they received services, the convenience of CRC services, the responsiveness of staff to their needs, and their satisfaction with each service (including written materials and education programs). Each CRC distributed the survey forms (in English and Spanish) to clients in the sample; caregivers returned the anonymous surveys directly to the SRC, which analyzed the data and shared aggregate results with each CRC.

COST AND AMOUNT OF SERVICE PROVIDED

In FY 2004-05, the total contract award from DMH to the 11 CRCs and the SRC was \$11,747,000 (\$10,859,209 to the CRCs and \$887,791 to the SRC). (See Appendix A, Site Distribution List, for a listing of site names, host agencies, and counties covered.)

With DMH funds, the CRCs and the SRC provided an array of services and functions, as described in the following sections. Funding used for the purchase of services (respite, legal consultation, counseling, Link2Care, and transportation) represents 25 percent of the total CRC contract amount.

CRC Services

The Caregiver Resource Centers provide a single point of entry for families caring for adults with cognitive impairment. Through the CRC system, families may access crucial information about the condition affecting their loved one, community resources, respite, counseling and emotional support, education, training, and legal and financial advice. The CRCs work closely with a full range of community organizations to address the diverse needs of caregivers. Over time, a caregiver faces new challenges; help from the

CRC continues until a family no longer needs assistance. The relationship between the family and the CRC may last for many years. A sampling of comments provided by caregivers in response to the CRC 2004 Satisfaction Survey shows how the CRC services are regarded:

“Words cannot express what a godsend your service has been. Your staff couldn’t be more effective or inspiring. Thanks to your service I know how to take care of myself as well as my husband. I’m learning to be more loving and compassionate and to roll with the punches. I can’t imagine what I’d do without this service. Thank you so much.”

“I am very happy for the help from Valley Caregiver [Resource Center]. I feel as if a heavy weight has been lifted off of my shoulder. I now can deal with my problems better. Thank you.”

“I firmly believe that, had it not been for the help given to me by the Family Caregiver Alliance, I would not have emotionally survived. The financial help I received helped me keep a helper to aid me in taking care of my husband, which kept me in better physical condition. The staff at the center helped emotionally as I felt I was near a breakdown. A mere thank you does not seem enough.”

Directly through their staff or through vouchers the CRCs provide:

- Information, advice, and referral;
- Uniform assessment of caregiver needs;
- Long-term care planning and consultation (“Family Consultation”): A combination of information and advice, planning, and problem solving that often includes emotional support and intervention with existing service systems;
- Legal and financial consultation with a contract attorney as part of the long-term care planning process;
- Mental health interventions, such as support groups, psychoeducational groups, and counseling:
 - Support groups typically are small group events that provide practical information that helps families to understand cognitive disorders, manage daily care, cope with stress, and plan for long-term care;
 - Psychoeducational groups are structured sequential class series that combine training on practical coping skills, self-care, and relaxation techniques;
 - Counseling offers more in-depth emotional support and mental health intervention beyond family consultation;
- Education and training programs, such as workshops and caregiver retreats;
- Respite care services through flexible and creative use of local resources including: home care; adult day care services; transportation; temporary

placement in a residential facility; and overnight camps; and⁸

- Online service for education, information, and support (“Link2Care”).

Along with providing centralized access to information about, and referrals to, local, state and federal programs, the CRCs engage in a variety of local planning and program development activities. CRCs coordinate with other organizations serving adults with cognitive impairment, their families, and caregivers; assist in identifying and documenting service needs; promote the development of necessary community programs regionally; and cooperate with the SRC and DMH in the implementation of the program.

SRC Functions

As required under law, DMH maintains a contract for the SRC functions. DMH contracts with Family Caregiver Alliance to be the SRC and perform these functions:

- Serve as the statewide information and technical assistance clearinghouse on adult-onset cognitive impairment and caregiving issues;
- Provide coordination with other statewide organizations that serve adults with cognitive impairment, their families, and caregivers;
- Develop and conduct training appropriate for: families, caregivers, service professionals; advocacy, 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 DMH in establishing criteria for and selection of Caregiver Resource Centers; and
- Provide technical assistance and consultation to Caregiver Resource Centers for service and program development.

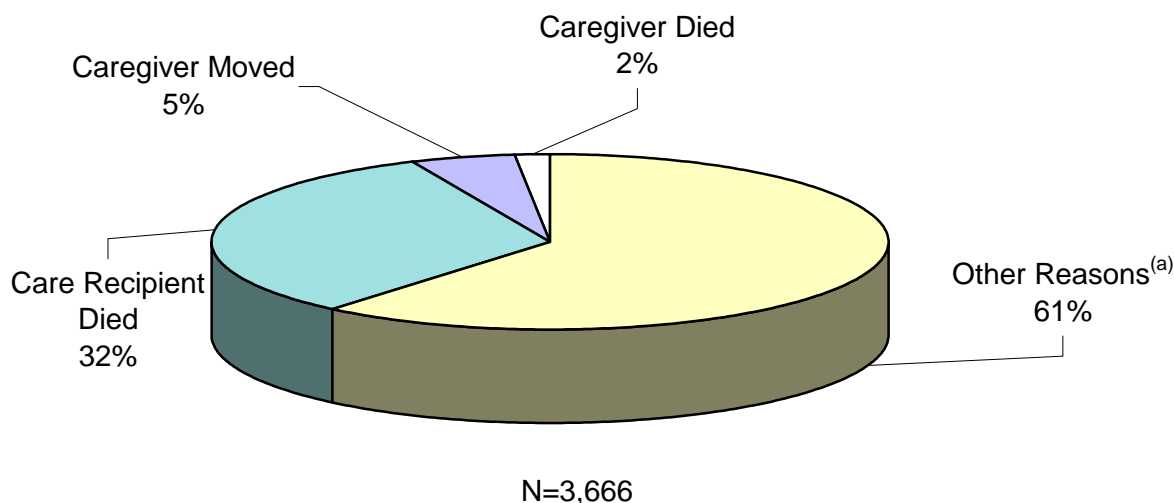
⁸ While some respite services are delivered to the care receiver, the services are designed to primarily benefit the family caregiver by relieving the caregiver's constant care responsibilities.

Cost and Service Findings

In FY 2004-05, 17,292 family caregivers received at least one CRC service, including: intake, assessment, family consultation, follow-up information and referral, counseling, legal consultation, respite assistance, Link2Care, psychoeducational groups, and support groups (see Table 1). Some of these caregivers were new to the CRCs and received an intake and basic information but wished no further assessment or service. Others went on to complete an assessment and became part of a CRC's active caseload for the year, joining caregivers already being served.

- The average amount of service per caregiver, among those who used one or more of the “core” CRC services, was 25.3 hours. Excluding respite, the average was 7.3 hours (see Table 1; Tables begin on Page 32).
- The active caseload of clients who had been assessed and were receiving services (or waiting for respite) reached 12,408 during FY 2004-05. During the year, 3,666 cases were closed. About one-third (32 percent) of these cases were closed due to the death of the care receiver and one-seventh (14 percent) were closed due to out-of-home placement of the care receiver (see Figure 1 and Table 2).

Figure 1. Percent of Closed Cases by Reason, FY 2004-05

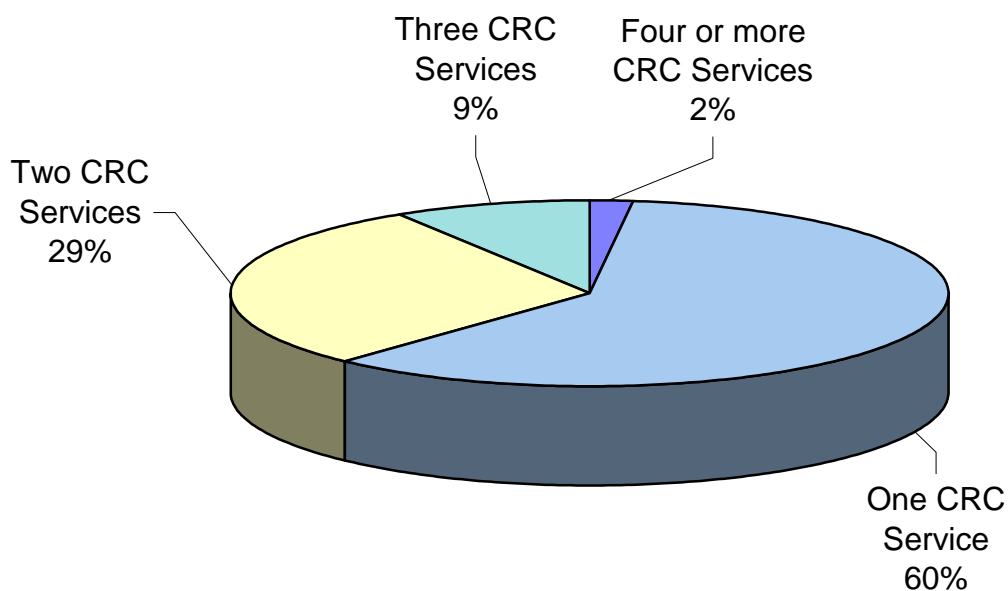


^a “Other Reasons” include families who declined further services or who could not be reached for a reassessment after multiple contacts.

- In all, 6,988 new family caregivers completed the intake process; 3,869 went on to have full, usually in-home, assessments of their needs. The CRCs provided 7,893 reassessments (full reassessments for 4,384 caregivers and updates due to status change for 3,509) (see Table 3).

- The most-used core services were family consultations (used by 11,859 families); follow-up information and referral (5,839); respite care (1,747); Link2Care (1,280); and support groups (972). The average length of time for a family consultation was 3.0 hours; the average time for follow-up information and referral was 0.8 hours; and the average amount of respite per user was 153 hours. The average time spent attending a support group was 8.8 hours. This year, specialized support groups were offered for particular types of caregivers, including: adult children caregivers; caregivers of stroke patients and early-onset Alzheimer's patients; and Spanish speakers and gay men (see Tables 3 and 5).
- The majority of family caregivers (60 percent) used only one service beyond intake and assessment in FY 2004-05, which is the same proportion as in FY 2003-04. The percentage of family caregivers utilizing two services decreased from 31 percent in FY 2003-04 to 29 percent in FY 2004-05, and the proportion of family clients using three or more services increased to 9 percent (see Figure 2).

Figure 2. Family Caregivers Receiving Services from CRCs by Number of Services, FY 2004-05^a



N = 15,156

^a Includes CRC "core" services only (family consultation, follow-up information, counseling, psychoeducational groups, support groups, family-focused education, legal consultation, and respite). The Link2Care online system and access services (intake, assessment, and reassessment) are excluded.

- Overall, among all services tracked by hours, respite care had by far the highest usage at 267,956 hours. Among the respite care options, in-home care was used most: 183,784 hours (see Table 4).
- Ten CRCs offered legal/financial consultation and 312 caregivers took advantage of this service, which is up 15 percent from last year. The average time per consultation for each caregiver was 1.75 hours (see Table 3).
- In all, 214 caregivers received individual counseling this year, down from 227 last year (a 6 percent decrease). The average time spent in counseling was 4 hours, which is down 13 percent from last year's 4.6 hours (see Tables 3 and 5).
- Psychoeducational groups offered by 10 CRCs served 604 caregivers this year (about the same as last year's 599). The average time a caregiver spent in such a group was 10.2 hours (44 percent less than the 18.3 hours in FY 2003-04) (see Tables 3 and 5). In all, 301 group sessions were held throughout the state during the year. Examples of the topics are: "Taking Care of You—Powerful Tools for Caregiving" (152 sessions); "It Takes Two: A Refreshing Approach to Understanding Dementia Behavior" (64 sessions); and "Controlling Your Frustrations" (40 sessions).
- A total of 14,821 family caregivers received family-focused education and training to help them understand cognitive disorders, manage daily care, cope with stress, and plan for long-term care. Across the state, 300 different training events were held (in addition to the psychoeducational groups). The topics were diverse. Among the most popular were basic caregiving skills (40+ sessions); long-term care planning, including legal issues (25 sessions); coping and stress management (20+ sessions); communication and behavior management with dementia (17 sessions). A sampling of specialized family-related topics include: "Children of Toxic Agers—Learn How to Love and Heal," "When Everyone Talks and Nobody Listens: Working Together with Your Siblings," "Helping Children and Young Adults to Understand Dementia: A Workshop for Parents," and "How to Hold a Family Meeting."
- In FY 2004-05, 1,280 caregivers participated in Link2Care, the web-based support and education program. All were registered in the online support group.

SERVICE DEMAND AND CRC SUCCESS IN MEETING DEMAND

To assess the nature and extent of the demand for services that support caregivers, and to evaluate the CRCs' success in meeting this demand, several questions are relevant. First, how many caregivers are seeking services from the CRCs and which services do they want? Second, are all the services they need available? Third, are caregivers satisfied with the services?

The answer to the first question, the number of caregivers receiving services from the CRCs during FY 2004-05, has been provided in the previous section.

To answer the second question, that of need, requires additional information about the caregivers themselves and their situations, including the problems facing the adults for whom they are caring. Further, it entails knowing whether a needed and desired service exists at all and, if it exists, the extent to which the caregiver must wait for this service. In the findings section that follows, descriptive statistics are provided about the caregivers and care receivers served by the CRCs in FY 2004-05 and the need for services identified during the initial contact with the CRCs (at intake). Information is then presented about the gaps in service and unmet needs identified by each of the CRCs in their service areas, as well as about the wait for a key service, respite care.

Finally, to assess whether caregivers believe the CRCs are meeting their needs requires information from the caregivers about their experience in getting help from the CRCs. Findings from the CRC 2004 Satisfaction Survey completed during the year are presented below.

Service Demand Findings

Key findings about service demand from intake information and the assessment database follow. Comparable data from 1990 are provided wherever possible to show how the CRCs' service population has changed over time.

Caregivers

The average caregiver served by California's CRC system is a 58-year-old woman who has been caring for her father or husband with Alzheimer's disease for a time period of one to two years. The greatest caregiver needs, as reported during intake, are for general information/orientation (68 percent), emotional support (58 percent), and respite care (53 percent). Other expressed needs are for financial advice and aid (21 percent), help in managing the care receiver's behavioral problems (17 percent), and legal assistance (17 percent) (see Table 13).

- Caregivers range in age from 17 to 99 years, with the average age of 58. In comparison, in 1990, the average age was 61. The largest group (43 percent) is age 60 or older, with 16 percent 75 years or older. About one in four (26 percent) are between 36 and 50 years old.
- Most often, caregivers are the adult children (46.5 percent) of the care receiver, but about one in three (34 percent) is the spouse and one in ten (9.5 percent) has another (non-family) relationship with the care receiver. Family caregivers are most likely to identify themselves as the "primary" caregiver (88 percent) and to live with the care receiver (69 percent). In 1990, the distribution of relationships was spouse (55 percent); daughter (16 percent); and other, including sons, other

- relatives, and non-relatives (29 percent). A much higher proportion lived with the care receiver (87 percent).
- The majority of family caregivers served by the CRCs are White (68 percent). However, CRC caregivers are increasingly diverse. Caregivers served report their ethnicity as Hispanic (14 percent), African American (9 percent), Asian/Pacific Islander (6 percent), and other ethnic groups (3 percent). In 1990, the ethnic distribution was White (88 percent), Hispanic (4 percent), African American (5 percent), and other (3 percent).
 - Nearly half (47 percent) of caregivers under the age of 65 also work outside the home, full time (33 percent) or part time (14 percent). In 1990, 28 percent of caregivers were employed outside of the home.
 - Depression is a problem for family caregivers. More than four in ten (45 percent) of CRC family caregivers show clinical symptoms of depression.⁹ Caregivers generally report high stress due to their caregiving situation, regardless of their care receiver's specific diagnosis. More than half (56 percent) of caregivers self-report feeling "depressed" or "anxious." Overall, 53 percent of caregivers score in the "high burden" range on the Adapted Zarit Interview in the caregiver assessment.
 - Half (50 percent) of caregivers say their physical health is now worse than it was six months before. About one-third of caregivers (34 percent) report their health is "fair" or "poor." The leading health problems among caregivers are high blood pressure (experienced by 31 percent of caregivers), back and neck problems (26 percent), arthritis (26 percent), sleep disturbance (19 percent), cardiovascular disease/heart trouble (13 percent), and diabetes (10 percent).
 - Caregivers provide an average of 85 hours of care each week—about 12.2 hours/day, seven days a week. They receive little help from others—an average of 8.4 hours weekly (1.2 hours per day).

Care Receivers

- Care receivers range in age from 19 to 105 years old, with an average age of 74. Ninety percent of care receivers are age 60 or older. The majority (84 percent) are at least 65 years of age; three-fifths (60 percent) are 75 years of age and older; and nearly one quarter (24 percent) are at least age 85. In 1990, the average age of care receivers was 70.
- More care receivers are female (56 percent). In contrast, in 1990, most (60 percent) care receivers were male.
- Few care receivers live alone (12 percent) or in nursing homes (3 percent) when the caregiver first contacts a CRC for assistance.

⁹ As evidenced by scores of 16 or higher on the Center for Epidemiological Studies Depression Scale (CES-D).

- The median annual household income range for the care receiver population was between \$20,000 and \$39,999—well below California’s median income, which was \$67,814 for a family of four in 2003 (the most current data year).¹⁰
- More than half (56 percent) of care receivers have a degenerative illness, principally Alzheimer's disease (26 percent), but also Parkinson’s disease (2.4 percent), Huntington’s disease (0.2 percent), and other dementias and/or degenerative diseases (27 percent). Of the remaining care receivers, 30 percent had suffered a stroke, 7 percent are traumatic brain injury survivors, and 6 percent have brain tumors or other non-degenerative disorders. The vast majority of care receivers (97 percent) have a confirmed diagnosis. To compare, in 1990, the diagnostic distribution was as follows: Alzheimer’s disease (37 percent); all other dementia and/or degenerating diseases (28 percent); stroke (22 percent); traumatic brain injury (8 percent); and brain tumor or other non-degenerative diseases (3 percent). Data on confirmed diagnosis was first collected in 1994, when the proportion of care receivers with a confirmed diagnosis was 85 percent.
- Caregivers now wait less time before contacting a CRC for help. In the past decade, the time between the date of diagnosis and a call to a CRC has decreased from five years to two years. In FY 2004-05, 73 percent of care receivers experienced the onset of their disease/disorder less than two years ago; only 2 percent has lived with their cognitive disease/disorder for 11 years or longer. In 1990, the average number of years since onset was five years.
- Care receivers have significant care needs. They have an average of ten functional problems related to not being able to perform daily tasks. The most frequent problems reported are related to taking medications, managing money, preparing meals, performing chores, staying alone, bathing, and dressing.
- As reported by their caregivers, care receivers have multiple memory and behavior problems, which are commonly due to cognitive deficits. At the time of assessment, more than half of caregivers reported the following as having occurred in the past week:
 - Asking the same question over and over;
 - Losing or misplacing things;
 - Trouble remembering recent events;
 - Forgetting what day it is;
 - Difficulty concentrating on a task;
 - Appearing anxious or worried; and
 - Appearing sad or depressed.
- Of the care receiver’s problems, the following were the most bothersome or upsetting to their caregivers:
 - Engaging in behavior that is potentially dangerous to self or others;
 - Arguing, complaining, and/or irritability;
 - Appearing sad or depressed;
 - Acting aggressively toward others verbally; and

¹⁰ U.S. Census Bureau, 2005. From <http://www.census.gov/hhes/income/4person.html>

- Expressing feelings of hopelessness or sadness about the future.

Availability of Services

Inadequate Respite Services. Caregivers in all parts of California continue to lack adequate opportunities for respite care. The number of caregivers on the waiting list in FY 2004-05 for respite care through the CRCs has grown to 5,159 (from 4,910 in FY 2003-04), with the average waiting time now nearly two and a half years (29 months) (see Tables 3 and 4). The CRCs report:

- There is insufficient funding to meet the demand for assisting family caregivers to pay for respite, whether in-home or through adult day care. “When I needed respite help, you didn’t have the money,” said one caregiver in responding to the CRC 2004 Satisfaction Survey. Another said, “I was put on a waiting list for help when I needed help ASAP!” The lack of Medi-Cal funding for Alzheimer’s day care programs continues to be a problem.
- A problem for working caregivers is the lack of affordable all-day respite options.
- Caregivers in rural areas have an especially difficult time getting respite care. Availability of adult day care is lacking in many rural settings, which is especially challenging for working caregivers. Some areas have no respite providers of any kind (for example, Siskiyou County’s Scott Valley and Tulelake). Many home health agencies have no staff in rural areas to provide in-home respite, and there are also no Senior Companions.¹¹
- As aged and frail care receivers require a higher level of care from caregivers, including more personal care, the lack of respite becomes a more serious problem.
- Many caregivers cannot get respite because their care receivers have diabetes or another condition that requires dispensing medication. In-home care companies are unable to provide workers who are authorized for this type of care.
- It is difficult for caregivers to obtain help in small increments to assist with activities of daily living. Most agencies require a four-hour minimum or charge a much greater fee to provide two hours of help.
- The lack of affordable home care remains a major problem.

Other Service Needs. In addition to a lack of respite options, families living in rural areas throughout California have a great, unmet need for transportation services. Other needs in rural areas are for support groups, mobile crisis units, and disaster preparedness for medically fragile individuals.

¹¹ Senior Companions are volunteers age 60 or over who help adults with special needs to remain independent and living in their own homes; they also offer respite for caregivers.

Other unmet needs of caregivers include the need for affordable counseling services—both extended and brief (six one-hour sessions)—and the need for help with outside chores and minor home repairs. More support groups are needed at convenient times (including evenings and weekends) and places, and for particular groups of caregivers and care receivers, such as early stage Alzheimer’s and Parkinson’s disease.

Support now available through the National Family Caregiver Support Program administered by the Area Agencies on Aging has been helpful to many caregivers. At the same time, it leaves out a significant group of caregivers: Younger caregivers and those caring for a younger adult cannot access needed support from the AAAs. In addition, families who use In-Home Supportive Services (IHSS) are ineligible for respite from the CRCs. For this reason, very little is available to them in the way of financial support. Whether the care receiver’s problem stems from a traumatic brain injury or from Huntington’s disease, similar gaps confront the caregiver, including:

- An absence of affordable residential care (board and care and Medi-Cal skilled nursing) for persons with TBI and Huntington’s disease, and for younger persons with brain impairments. Augmented board and care homes are particularly needed for this population;
- A lack of supportive services for TBI—recreational, social, and rehabilitation services. There are too few TBI day programs that are low cost or Medi-Cal certified and there are not enough case management services for TBI survivors.
- lack of support groups for caregivers of TBI patients that include day care or respite services to make attendance by caregivers more feasible.

In our increasingly diverse state, more and more caregivers do not speak English and need specialized bilingual services. The CRCs point to the following unmet needs:

- Support groups specifically for Asian caregivers;
- Support groups for Chinese-speaking clients in Bay Area for all diagnoses;
- Filipino and Korean literature on caregiving;
- German-speaking social workers in the Palos Verdes area; and
- Low-cost counseling and “Powerful Tools” classes in Spanish.

Caregivers continue to have great difficulty accessing adequate care for their loved ones’ medical and dental problems. The CRC’s cite unmet needs for:

- Mobile or in-home dental services; and
- Geriatric physicians.

Finally, affordable out-of-home placement is hard to find, especially for persons with behavioral problems.

Caregiver Satisfaction with CRC Services

To the CRC 2004 Satisfaction Survey, 1,355 randomly selected family caregiver clients responded (a response rate of 31 percent). Respondents had received services from the CRCs for varying lengths of time: about half (49 percent) responded “over 12 months” and 8 percent said “less than a month.” Slightly more than half (52 percent) were receiving services at the time of the survey. Other key points include:

- The vast majority (97 percent) of caregivers were “satisfied” or “very satisfied” with the overall quality of services received from the CRCs; and
- Nearly all (98 percent) said they would recommend the CRC to others.

Caregivers also said:

- Staff showed respect (99 percent) and were courteous and helpful (96 percent); and
- Appropriate questions were asked to determine the caregiver’s need (97 percent), and staff worked with them to decide what help might best meet the needs for their particular situation (96 percent).

To identify opportunities for improvement, caregivers were asked about their satisfaction with individual services. While most caregivers had used only a few of the services, users of each service generally were quite satisfied. The satisfaction percentages for each service (presented in order of number of respondents) are:

- Written materials, 98 percent (952 respondents);
- Ongoing caregiver consultation, 96 percent (815 respondents);
- In-home respite, 93 percent (537 respondents);
- Education programs, 95 percent (505 respondents);
- Support groups, 95 percent (495 respondents);
- Legal or financial consultations, 93 percent (433 respondents);
- Individual or family counseling, 93 percent (326 respondents);
- Adult day care respite, 94 percent (279 respondents);
- Link2Care, 92 percent (208 respondents);
- Caregiver retreat, 94 percent (168 respondents);
- Out-of-home respite (nursing home and assisted living), 86 percent (137 respondents); and
- Camps for care receiver, 88 percent (96 respondents).

PROGRAM IMPACT

To assess the program's effectiveness in deterring institutionalization of adults with brain impairments, promoting continued quality of care for adults with cognitive impairment, and enabling caregivers to maintain a more normal routine, several types of information are relevant.

As to the extent to which the program is deterring institutionalization, one need only look at the characteristics of the care receivers who are being cared for at home. Their profile mirrors the factors for admission to intermediate care facilities or skilled nursing facilities (Title 22, Sections 51334 and 51335), as articulated by the Department of Health Services Office of Long-Term Care.¹²

A recent study of IHSS users focused on those who were most likely to have a long-term placement in a nursing facility.¹³ Among the characteristics leading to placement were dementia, Parkinson's disease, or stroke (which increased chance of institutionalization by 163 percent, 78 percent, and 52 percent, respectively); requiring assistance with toileting (which increased placement chance by 49 percent); and having impaired judgment (which increased chance by 40 percent). Most of the CRC system's care receivers clearly share the characteristics of these nursing home users. Yet a surprisingly low number do get placed in nursing homes: Only 331 were placed in FY 2004-05, or 3 percent of the caseload (see Table 2). The CRC system, by helping caregivers, appears to be deterring institutionalization of care receivers.

The CRC 2004 Satisfaction Survey provides valuable data from caregivers about how the CRCs promote continued quality of care and enable caregivers to maintain a more normal routine, which in turn helps in deterring institutionalization.

- Most (94 percent) caregivers felt they were able to deal more effectively with daily caregiving problems and better understood the disease/condition of the person for whom they care.
- Most (93 percent) felt better equipped to deal with a care crisis and felt confident that help was available if needed.
- Most (92 percent) said they now know how to take better care of their own needs as caregivers. As a result of working with a CRC, the majority (89 percent) of caregivers are now taking better care of their own health.

¹² Williams, Shirley. *Project Overview: Nursing Facility Eligibility*. From www.ltcucla.edu/toolkit/nfcertifiability.ppt

¹³ Kim, Jung Ki and Atkins, Sandy. *Research Brief #: Risk Factors for Long-term Nursing Facility Placement among Dually Eligible IHSS Users Aged 65+*. UCLA Center for Long Term Care Integration: 2003. www.ltcucla.edu

CRC SYSTEM STRATEGIC PLAN AND ACHIEVEMENTS

The statewide strategic plan—developed jointly by the CRC directors, DMH, and the SRC—provides a vision for the CRC system. Below are the identified system goals and this year’s accomplishments.

GOAL A: Advocate for using public and private resources to the maximum benefit for California caregivers.

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

All CRCs continued to take local leadership roles and collaborate to increase understanding about the needs of family caregivers and resources to help them. Some of the tangible results include:

- A three-part regional series on public benefit resources and procedures provided for the Multiple Sclerosis Society (Coast CRC);
- “Together We Find the Answers: Making Appropriate Care Decisions”—a forum for the Santa Barbara Association of Health Care Providers (Coast CRC);
- Caregiver training for low-income, IHSS family caregivers, in collaboration with the Sacramento County Public Authority (IHSS) (Del Oro CRC);
- Training of respite providers at the Area 4 Agency on Aging (A4AA) quarterly meeting on male caregivers and unique characteristics of men who provide care (Del Oro CRC);
- A new support group for Latino social workers (“Latinos Visibles”) who work in the field of aging (Bay Area CRC);
- A caregiver conference in Ontario held in collaboration with AARP (Inland CRC);
- Inclusion of caregiver issues as part of the Los Angeles County service providers’ training program, MENTORS (Los Angeles CRC);
- A report on “Gaps in Respite Services” from the Los Angeles Long-Term Care Coordinating Council’s workgroup on caregiving and kinship care (Los Angeles CRC);
- Website links for the new Los Angeles County website (Los Angeles CRC);
- Inclusion of caregiver issues in local needs assessments (especially Del Oro, Bay Area, Mountain, and Valley CRCs);
- New caregiving coalitions (Mountain, Orange, Redwood, and Southern CRCs); and
- Presentation on issues of diversity and caregiving at the White House Conference on Aging (Los Angeles CRC).

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

In the past year, the CRCs' advocacy efforts focused particularly on county mental health systems and Proposition 63 planning (Coast and Valley CRCs); the AAAs (Bay Area, Del Mar, Del Oro, Los Angeles, and Southern CRCs); physicians serving seniors and adults with brain impairments (Del Oro and Redwood CRCs); and legislators and their aides (Del Oro, Inland, Orange, and Southern CRCs). In particular, Del Oro CRC took advantage of its Sacramento location by:

- Coordinating a monthly support group at the state capitol with sponsorship from the office of Senator Deborah Ortiz to promote awareness and to address caregiver issues, support, and resources;
- Cosponsoring the Longevity Fair with California State University's Department of Gerontology, which was attended by more than 300 people; and
- Conducting outreach with the CalPERS Wellness Committee to provide caregiver information and services to state employees who are family caregivers.

The Bay Area CRC made headway on behalf of special groups of caregivers by:

- Participating in the Robert Wood Johnson Foundation's Latino Partnership; and
- Serving on the San Francisco Long-Term Care Task Force's Lesbian, Gay, Bi-Sexual, and Transgender (LGBT) Advisory Committee.

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.

Over the past year, many of the CRCs moved ahead in using the Internet to communicate with one another and with caregivers. The online program, Link2Care, is available as a client service throughout California. The number of caregivers actively participating in Link2Care during FY 2004-05 was 1,280. Promoting and participating in the "Ask the Expert" component of Link2Care was an important activity at several CRCs (Bay Area, Southern, and Valley CRCs). Also, the Southern CRC worked with the *San Diego Union Tribune* to develop an "Ask the Expert" online program as part of an online support group.

Other achievements ranged from making arrangements through the Internet for the master trainer program for the "Powerful Tools" training series for caregivers (Coast CRC) to rolling out a new systemwide website, the California CRC website (www.cacrc.org)—developing links between it and individual CRC websites and offering

public web seminars on grief and loss and mild cognitive impairment (Bay Area CRC). Other key developments include:

- Enhancing individual CRC websites: launching a website with a searchable database (Inland CRC); putting recent newsletter articles and an educational events schedule online (Bay Area, Del Oro, and Inland CRCs); adding the ability to donate online (Del Mar and Del Oro CRCs); and running online support groups, including one for LGBT caregivers (Bay Area CRC);
- Upgrading internal systems: setting up an intranet and replacing routers with Cisco-based VPN appliances to improve speed and reliability of connection (Del Mar CRC);
- Responding to caregiver inquiries online after referral from website (Del Oro CRC);
- Using the Internet actively for research, public outreach, and communication with clients (Del Mar CRC); and
- Using newsletters to alert caregivers to other helpful websites to access information on diseases, treatment plans, and research (Del Mar, Del Oro, and Bay Area CRCs).

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

During the year, several CRCs worked with the SRC to test and evaluate Danic, the new electronic records system under development for the CRC system. Initial training for staff and super users was created. Due to technical challenges, implementation of Danic was delayed until FY 2005-06.

Objective 3: Enable all CRC staff (statewide) to utilize technology (for example, marketing, research, web-based services, and so on).

The CRCs actively used technology in their work during the year, including email to contact clients that work during normal business hours, identifying new web-based resources, announcing upcoming workshops to professionals using PDF files (Bay Area CRC). The Del Oro and Mountain CRCs and Family Caregiver Alliance collaborated to implement a rural training grant using telephone, web, and in-person methods to reach caregivers in rural communities.

Objective 4: Investigate internal CRC and strategic partnerships to enhance the use of assistive technology in service delivery.

During FY 2004-05, Coast CRC collaborated with San Luis Obispo County's Sheriff's Department to implement "Project Lifesaver," an electronic safe return program for people with dementia who are at risk for wandering. Work is underway to replicate the program in Santa Barbara and Ventura counties.

GOAL C: Build on best practices to expand service options and innovative programs.

Objective 1: Expand service options to meet the needs of a growing, and increasingly diverse, population of caregivers.

The CRCs collectively and individually devoted considerable effort to tailoring service options to the diversity of California’s caregivers. Accomplishments this year include:

- Forming a CRC statewide diversity committee;
- Providing training at the statewide CRC Staff Enrichment conference on “Working with diverse populations and cultural sensitivity in staff settings,” (Bay Area CRC) and “How to market and tailor services to diverse communities” (Del Oro CRC);
- Adding Spanish-speaking staff (Del Mar and Del Oro CRCs);
- Developing and distributing materials (such as brochures and fact sheets) for caregivers in other languages, including Spanish, Vietnamese, Japanese, and Chinese (Bay Area, Del Mar, Del Oro, Los Angeles, and Orange CRCs);¹⁴
- Developing and participating in ethnic-specific local committees to reach caregivers in these communities: Asian Pacific Islander Family Caregiver Services Committee (Bay Area CRC); Latino and African American Health Aging Summits (Del Oro CRC); and Latino caregiver coalitions (Inland and Mountain CRCs);
- Offering customized training for special groups of caregivers, including: “Powerful Tools” and “There Must Be a Better Way Than This” especially for the African American community (Bay Area CRC); Spanish-language versions of “It Takes Two” and “Controlling Frustration” (Bay Area CRC); and the first legal workshop in Spanish (Los Angeles CRC);
- Providing new culturally sensitive support groups for Spanish speaking clients (Inland and Valley CRCs) and gay men (Los Angeles CRC);
- Developing an education planning committee with rural representation to incorporate specific needs of these communities (Mountain CRC);
- Training employees at Consolidated Tribal Health Clinic in Mendocino County regarding caregiving issues (Redwood CRC); and
- Offering services (such as consultation and support and psychoeducational groups) during evening hours to accommodate working caregivers (Redwood CRC).

¹⁴ Spanish language materials include three legal fact sheets: “California Advance Healthcare Directives;” “Driving, Dementia, and California Law;” and “Protective Proceedings.”

Objective 2: *Establish a catalog of information on the planning and development of culturally sensitive and competent education/training events for statewide distribution.*

The CRCs individually reviewed their inventory of culturally appropriate materials and submitted items for statewide dissemination at the CRC staff development conference in January 2005.

GOAL D: Demonstrate CRC program effectiveness through caregiver outcomes.

Objective 1: *Establish Performance Outcomes Task Force.*

The Performance Outcomes Task Force (POTF) was established and held its first meeting during FY 2004-05. The POTF conducted a session on developing caregiver action plans at the CRC staff development conference in January 2005. Also, Orange CRC focused on applying outcome measures to community education events and exploring methods to measure respite outcomes; Southern CRC continued to discuss outcomes as they relate to the disease management model; and the SRC, with the cooperation of all 11 CRCs, conducted the CRC 2004 Satisfaction Survey.

Objective 2: *Investigate ways to use Danic to improve caregiver outcomes by utilizing data trends.*

Danic is slated for implementation in FY 2005-06.

GOAL E: Promote development of statewide educational programs for family caregivers.

Objective 1: *Select a minimum of three areas in need of education and training development statewide.*

The CRCs implemented statewide training on “Powerful Tools,” “It Takes Two,” and “To Place or Not to Place.” The request for these classes has been constant. CRCs sent staff to a master training for the “Powerful Tools” class and set up training for staff as class leaders to expand the ability to offer this popular series.

The CRC Education Committee mapped out training for FY 2005-06. Topics include care plan development, Danic implementation, clinical supervisor master training, diversity issues, quality assurance, and service units definition. These programs will take place in FY 2005-06.

Objective 2: Establish best practices for caregiver retreats and care receiver camps.

Two CRCs shared their experiences with coordinating retreats for caregivers who do not speak English, including a Spanish-language caregiver retreat (Los Angeles CRC) and a Vietnamese caregiver retreat (Orange CRC). Orange CRC also provided information about two other models, including a 48-hour retreat program and a caregiver day retreat.

Objective 3: Disseminate information on culturally sensitive and competent educational events.

Accomplishments for the year are reported under Goal C, Objective 1.

Objective 4: Hold a statewide staff development conference.

The SRC convened the CRC Staff Enrichment Conference on January 10-12, 2005 in Sacramento. The conference included workshops on caregiver issues such as talking to loved ones about end-of-life care, discussing placement, and understanding dementia behavior. Also discussed were issues such as developing philanthropic relationships with clients, developing professional-level PowerPoint presentations, and strategies for embracing diversity. Facilitated roundtable discussions were held on such topics as caregiver retreats; using technology for caregiver education, communication, and emotional support; and integrating new program funding.

RECOMMENDATIONS

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 ethnic and rural caregivers.
2. Promote public policy that advances the consumer-directed model of care for all caregivers and care receivers.
3. Promote policies that recognize and assess family caregivers as part of transitional (hospital/SNF to home) and long-term care planning.
4. Utilize one CRC Uniform Client Record System to monitor and promote targeted outcomes for caregivers.
5. Improve assistance to working and isolated caregivers via technology. For example, increase the number of caregivers using the Internet-based Link2Care program.
6. Explore the idea of establishing liaisons with the private sector to provide caregiving resources to caregivers working outside the home.

7. Work cohesively with statewide groups to address the need for appropriate and affordable long-term care options for care receivers and their family caregivers. Improve the situations of care receivers and their family caregivers through public awareness and the development of affordable, accessible, and culturally appropriate long-term care services.
8. Identify viable program options for traumatic brain injury caregivers and their loved ones.
9. Carry out CRC research to: (1) measure and analyze the impact of cognitive disorders on family and caregiver well being; (2) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers; and (3) evaluate new modes of communication, support, and education for caregiver families.
10. 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)
 07/01/2004 through 06/30/2005

	Total	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total # of family clients receiving at least one CRC service ^a	17,292	2,957	1,383	3,099	1,519	1,564	1,745	715	669	1,858	784	999
Total # of family clients receiving CRC core Services ^b	16,013	2,856	1,339	2,994	1,082	1,496	1,732	676	644	1,787	745	662
Avg. # of hours across ^c CRC core services (excluding respite)	7.3	4.1	5.6	3.2	6.3	2.7	4.2	8.6	10.6	25.4	6.0	8.5
Avg. # of hours across ^d CRC core services (including respite)	25.3	16.6	26.9	21.9	25.4	15.9	20.2	31.9	33.0	37.6	38.3	44.3

a Unduplicated count of clients using services including intake and assessment/reassessments. 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 = 8,264. Based on the number of clients receiving "core" services (N =10,476) minus respite users (N = 2,212).

d N=10,476. Based on the number of clients receiving "core" services, as noted above in "b."

TABLE 2
CAREGIVER RESOURCE CENTERS
CLIENT STATUS SUMMARY
07/01/2004 through 06/30/2005

	Total	Bay Area CRC	Redwood	Los Angeles	Inland	Del Oro	Southern	Coast	Mountain	Valley	Del Mar	Orange
Total Active Clients at Start of Report Period	8,337	1,417	799	1,520	524	947	963	307	362	866	297	335
# New Clients Added	4,009	664	441	557	307	340	435	144	230	580	168	143
# Client Reactivated ^a	62	30	1	3	0	1	12	4	1	6	3	1
Total Active Clients During Report Period ^b	12,408	2,111	1,241	2,080	831	1,288	1,410	455	593	1,452	468	479
# Newly Inactive Cases	17	0	0	0	17	0	0	0	0	0	0	0
# Cases Closed	3,666	944	430	424	46	328	382	180	183	338	169	242
Reason closed												
--Caregiver died	65	1	11	6	1	19	6	3	3	6	8	1
--Caregiver moved	176	41	10	27	3	16	20	12	9	17	14	7
--Patient died	1,184	197	71	218	22	129	144	59	71	168	50	55
--Other ^c	2,241	705	338	173	20	164	212	106	100	147	97	179
# Patients placed in facilities	531	69	13	40	7	70	69	65	61	96	21	20
--SNF	337	43	11	37	5	18	46	36	43	75	13	10
--Rehab	2	0	0	0	0	0	2	0	0	0	0	0
--Acute Hospital	1	0	0	0	0	0	0	0	0	1	0	0
--Board & Care	153	26	2	3	2	19	20	28	15	20	8	10
--Other	38	0	0	0	0	33	1	1	3	0	0	0
Total Active Cases at End of Report Period ^d	9,097	1,598	1,089	1,567	514	970	1,024	327	430	961	277	340

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. 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..

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 3
CAREGIVER RESOURCE CENTERS
SERVICES SUMMARY: NUMBER OF CLIENTS REC'ING EACH SERVICE ^a
07/01/2004 through 06/30/2005

Program Services ^b	Total Clients Served	Average # of Clients Served ^c	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Intake ^d	6,988	635	1,182	582	1,426	645	425	551	252	236	822	355	512
Follow-up I&R	5,839	584	1,181	556	1,433	0	525	420	247	232	707	369	169
Assessment	3,869	352	631	441	540	259	309	431	144	230	580	163	141
Reassessment													
Full Reassessment	4,384	399	1,090	340	630	307	308	366	167	179	729	94	174
Status Change	3,509	319	543	156	533	317	382	401	131	191	511	195	149
Family Consultation	11,859	1,078	2,016	1,047	1,903	890	1,206	1,296	479	532	1,473	543	474
(Avg. number per month)	2,828	257	314	253	329	168	256	372	177	153	530	183	93
Counseling (Individual)	214	19	53	39	16	5	13	16	17	9	11	31	4
(Avg. number per month)	34	3	5	4	3	1	3	4	4	2	2	5	1
Legal/Financial Consult.	312	35	58	60	32	6	23	40	30	22	9	32	0
Psychoeducational Groups	604	60	98	128	63	0	19	29	40	34	166	10	17
Link2Care ^e	1280	128	237	75	169	175	106	273	45	76	50	---	74

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.

e Total number of active Link2Care clients during report period

TABLE 3
 CAREGIVER RESOURCE CENTERS
 SERVICES SUMMARY: NUMBER OF CLIENTS REC'ING EACH SERVICE (CONT'D)
 07/01/2004 through 06/30/2005

Clients Receiving Program Services by Type of Service	Total Clients Served	Average # of Clients Served ^f	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Respite Care	1,747	159	150	183	194	123	172	184	88	129	251	178	95
Respite: Adult Day Care	214	19	13	34	8	9	38	11	9	23	19	37	13
Respite: In-home	1,451	132	91	150	180	104	136	173	77	116	199	146	79
Respite: 24-hour (out of home)	34	--	17	2	0	9	0	0	0	0	4	0	2
Respite: 24-hour (in-home)	78	--	36	10	0	0	6	0	2	0	15	0	9
Respite: Camp	85	--	72	13	0	0	0	0	0	0	0	0	0
Respite: Transport	12	--	0	0	0	0	0	0	0	0	1	10	1
Respite: Other ^{gh}	69	--	3	0	9	0	0	0	0	3	40	14	0
Respite (Avg. number per month)	640	58	46	62	72	32	68	76	35	51	81	70	47
Respite Wait List	5,159	469	821	627	960	152	628	398	275	249	714	91	244
Caregiver Retreat	365	33	45	0	51	0	10	0	0	45	128	12	74
Support Groups (Avg. number per month)	972	88	10	141	52	27	77	133	94	102	191	111	34
	270	25	8	40	17	7	10	42	29	33	42	33	9

f The statewide average is computed as follows: the number of family clients receiving the service divided by the number of CRC sites providing the service. For respite 24-hour out of home, 24-hour in-home, camps, transportation and other respite, averages were not calculated since less than half of CRC's had clients using these services.

g Includes group respite, provided on an hourly basis.

h For Respite 24-hour, Respite Camps, Transportation, and Other, Averages were not calculated since less than half of CRCs had clients using these services.

TABLE 4
 CAREGIVER RESOURCE CENTERS
 UNITS OF SERVICE DELIVERED
 07/01/2004 through 06/30/2005

Type of Service	Total Units Provided	Average # of Units Provided ^a	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Intake ^b	6,988 intakes conducted	635	1,182	582	1,426	645	425	551	252	236	822	355	512
Follow-up I&R ^c	4710 hours	428	683	562	902	0	504	293	695	152	495	291	133
Assessment	3,873 assess. conducted	352	631	441	540	263	309	431	144	230	580	163	141
Reassessment													
Full Reassessment	5,747	522	1,528	405	741	389	405	459	207	221	1,071	106	215
Status Change	3,555		548	156	535	325	382	404	131	203	525	197	149
	reassess. conducted												
Family Consultation ^c	35,437 hours	3,222	2,718	3,583	3,763	5,458	1,829	3,786	3,111	1,831	5,778	2,106	1,474
Counseling (Individual) ^c	862 hours	78	158	192	62	17	61	66	91	28	41	135	11

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

b Excludes provider/general community intakes

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

TABLE 4
CAREGIVER RESOURCE CENTERS
UNITS OF SERVICE DELIVERED (CONT'D)
07/01/2004 through 06/30/2005

Type of Service	Total Units Provided	Average # of Units Provided	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Legal/Financial Consultations	547 hours	61	229	60	46	0	20	40	42	22	9	79	0
Psychoeducational Groups ^d	6,312 hours	631	1,077	1,242	744	0	268	299	637	446	1,266	83	250
Total Respite ^e	267,956 hours	24,360	32,932	27,008	52,959	19,319	18,398	23,289	14,755	12,834	21,296	24,125	21,041
Respite: Adult Day Care ^f	7,553 days	687	721	905	450	407	1,132	718	301	668	255	1,585	411
Respite: In-home	183,784 hours	16,708	16,803	15,177	48,966	14,056	9,370	18,263	11,880	8,118	15,485	12,638	13,028
Respite: 24-hour ^g (out of home)	382 24 hr days	--	244	38	0	77	0	0	0	0	9	0	14
Respite: 24-hour (in home)	719 24 hr days	--	216	191	0	0	46	0	32	0	34	0	200
Respite: Camp ^d	170 24 hr days	--	144	26	0	0	0	0	0	0	0	0	0
Respite: Transportation	1,202 1-way trip	--	0	0	0	0	0	0	0	0	103	872	227
Respite: Other ^f	4,311 hours	--	42	0	843	0	0	0	0	40	2,994	392	0
Avg. # Months on Respite Wait List	N/A	29	23	16	15	84	85	10	24	13	15	9	28
Caregiver Retreat ^d	721 24 hr days	66	90	0	128	0	20	0	0	90	256	3	134
Support Groups ^d	8,523 hours	775	104	1,376	632	87	295	1,625	826	893	1,002	1,473	210

^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 5
CAREGIVER RESOURCE CENTERS
AMOUNT OF CRC SERVICE PER CLIENT (in hours)
07/01/2004 through 06/30/2005

CRC Service Type	Average Hours ^a	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Follow-Up I&R	0.8	0.6	1.0	0.6	0.0	1.0	0.7	2.8	0.7	0.7	0.8	0.8
Family Consultation	3.0	1.3	3.4	2.0	6.1	1.5	2.9	6.5	3.4	3.9	3.9	3.1
Counseling (Individual)	4.0	3.0	4.9	3.9	3.4	3.6	4.1	5.4	3.1	3.7	4.4	2.8
Legal/Financial Consult	1.8	3.9	1.0	1.4	0.0	0.7	1.0	1.4	1.0	1.0	2.5	0.0
Psychoeducational Groups	10.2	11.0	9.7	11.8	0.0	7.1	10.3	15.9	13.1	7.6	8.3	14.7
Respite Care ^b	415.6	715.9	435.6	735.5	542.4	270.6	306.4	421.6	251.6	262.9	344.6	447.7
Support Groups	8.8	10.4	9.8	12.2	3.2	3.8	12.2	8.8	8.8	5.2	13.3	6.2

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 total number of respite clients. The total amount of respite care per family client breaks down into 35 hours per month or 8 hours per week.

TABLE 6
CAREGIVER RESOURCE CENTERS
DEPRESSION AND HEALTH INDICES (FROM ASSESSMENT TOOLS)
07/01/2004 through 12/31/2004

CRC	Adapted Zarit Interview	CES-D	Experienced Anxiety or Depression in past 12 months?	How would you rate your overall health at this time?				Is your health worse than 6 months ago?
	Average score	Average score	Yes %	Excellent	Good	Fair	Poor	Yes %
Bay Area	16.6	17.2	42.8%	9%	63.3%	23.1%	4.6%	49.1%
Redwood	15.8	13.1	60.3%	18.6%	50%	26.2%	5.2%	44.4%
Los Angeles	18.7	16.8	64.3%	12.2%	47.4%	29.8%	10.6%	73.8%
Inland	20.7	17.8	54.5%	12.3%	49.4%	30.4%	7.9%	47.8%
Del Oro	15.1	11.3	49.7%	12.4%	58.8%	23.5%	5.3%	54.1%
Southern	16.8	15.8	52.1%	26.2%	49.6%	19.1%	4.9%	40.4%
Coast	20.1	16.7	65.5%	15.8%	45%	28.7%	10.5%	40.9%
Mountain	18.4	12.8	62.6%	16.7%	50.5%	24.3%	8.6%	47.4%
Valley	13.8	14.8	54.3%	10.9%	53%	27.2%	8.9%	54.9%
Del Mar	17.8	15.4	60.9%	15.9%	44.2%	31.9%	7.9%	50.4%
Orange	20.8	18.8	72.4%	17.2%	37.9%	34.5%	10.3%	37.9%
All CRCs	17.5	15.8	55.6%	13.1%	52.6%	26.7%	7.6%	50.3%

TABLE 7
 CAREGIVER RESOURCE CENTERS
 HOURS OF RESPITE CARE PROVIDED
 07/01/2004 through 06/30/2005

Respite	Total	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total Number of Family Clients Served	1,710	150	183	194	86	172	184	88	129	251	178	95
Average Monthly Respite Caseload ^a	640	46	62	72	32	68	76	35	51	81	70	47
Total Hours of Respite ^b	265,995	32,932	27,008	52,959	17,358	18,398	23,289	14,755	12,834	21,296	24,125	21,041
Average Number of Hours of Respite per Family Client	416	716	436	736	542	271	306	422	252	263	345	448
Average Number of Hours of Respite per Family Client per Month ^c	35	60	36	61	45	23	26	35	21	22	29	37
Average Number of Hours of Respite per Family Client per Week ^d	8	14	8	14	11	5	6	8	5	5	7	9

a Figure represents the total monthly caseload at all 11 CRCs statewide; the average monthly caseload across CRCs is 58 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 8
CAREGIVER RESOURCE CENTERS
EXPENDITURES FOR RESPITE VOUCHER SERVICES
07/01/2004 through 06/30/2005

Respite	Total	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total Cost of Respite Services ^a	\$2,517,265	\$290,484	\$244,962	\$528,589	\$180,510	\$194,024	\$218,316	\$151,381	\$152,679	\$218,594	\$170,610	\$167,116
Total No. of Family Clients	1,710	150	183	194	86	172	184	88	129	251	178	95
Total Contribution by Family clients ^b	\$272,299	\$20,952	\$34,334	\$44,715	\$15,103	\$31,126	\$19,214	\$26,067	\$23,583	\$26,063	\$23,750	\$7,392
Total No. of Family Clients Contributing Co-payment ^c	1,136	97	127	153	76	120	115	85	80	176	69	38
Percent of Families Contributing a Co-payment	65%	65%	69%	79%	88%	59%	63%	97%	62%	70%	39%	40%

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

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

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

TABLE 9
CAREGIVER RESOURCE CENTERS
EXPENDITURES FOR VOUCHER SERVICES
07/01/2004 through 06/30/2005

Expenditures ^a	Total \$	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Respite (Avg. \$ per family client)	\$2,517,265 \$1,441	\$290,484 \$1,937	\$244,962 \$1,339	\$528,589 \$2,725	\$180,510 \$1,468	\$194,024 \$1,128	\$218,316 \$1,187	\$151,381 \$1,720	\$152,679 \$1,184	\$218,594 \$871	\$170,610 \$958	\$167,116 \$1,759
Legal Consultation (Avg. \$ per family client)	\$38,219 \$122	\$12,232 \$211	\$4,990 \$83	\$6,077 \$190	\$600 \$100	\$1000 \$56	\$3,795 \$95	\$4,350 \$145	\$2,400 \$109	\$675 \$75	\$2,100 \$66	\$0 \$0
Counseling (Individual) (Avg. \$ per family client)	\$41,039 \$192	\$11,280 \$213	\$10,775 \$276	\$0 --	\$130 \$26	\$1,500 \$115	\$0 --	\$7,025 \$413	\$1,720 \$191	\$3,710 \$337	\$4,010 \$129	\$889 \$222
Link2Care Online Service (Avg. \$ per family client)	\$53,797 \$42	\$5,000 \$21	\$4,500 \$60	\$4,500 \$27	\$4,500 \$26	\$4,500 \$42	\$4,500 \$16	\$4,500 \$100	\$12,797 \$168	\$4,500 \$90	\$0 --	\$4,500 \$61
Other Vouchers ^b (Avg. \$ per family client)	55,261\$ --	\$1,328 --	\$0 --	\$2,017 --	\$21,698 --	\$0 --	\$0 --	\$4,690 --	\$0 --	\$426 --	\$0 --	\$25,103 --
Total	\$2,705,581	\$320,324	\$265,227	\$541,184	\$207,438	\$201,024	\$226,611	\$171,946	\$169,596	\$227,905	\$176,720	\$197,608

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 and other operational costs are excluded.

b. "Other" Vouchers include expenditures not covered by the other categories, e.g., Transportation. No average is provided because this category represents a combination of expenditures.

TABLE 10
 CAREGIVER RESOURCE CENTERS
 EDUCATION AND TRAINING ACTIVITIES
 07/01/2004 through 06/30/2005

Education/Training Activity Type	Total CRCs ^a	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
FAMILY-FOCUSED EDUCATION/TRAINING												
1. Total number of persons attending	14,821	2,272	412	1,045	34	4,398	2,793	94	236	2,348	210	979
OTHER EDUCATION/TRAINING EVENTS												
2. Total number of persons attending	7,889	711	642	2,937	0	391	1,430	25	536	870	267	80
ORIENTATION TO CRC SERVICES												
3. Total number of persons attending	14,052	15	1,573	590	0	1,031	4,267	29	84	5,087	1,031	337
Total	36,762	2,998	2,627	4,580	34	5,820	8,490	148	856	8,305	1,508	1,396

a Duplicated Count; the same person may attend more than one educational event during a fiscal year.

TABLE 11
 CAREGIVER RESOURCE CENTERS
 TOP TEN UNMET NEEDS/SERVICE GAPS IDENTIFIED
 BY CRCS IN THEIR SERVICE REGIONS
 07/01/2004 through 06/30/2005

NEEDS IDENTIFIED	# OF CRCS REPORTING
Respite Services	5
SNF/Residential Care (affordable)	4
Transportation	4
Adult Day Care	4
Support Group	4
Bilingual Services	4
Services in Rural Areas	2
Case Management Services	1
TBI Services and Resources	1
Counseling/Neuropsychological Services	1

TABLE 12
 CAREGIVER RESOURCE CENTERS
 MAJOR NEEDS/INFORMATION REQUESTED BY
 FAMILIES/CAREGIVERS AT CRC INTAKE ^a
 07/01/2004 through 06/30/2005

NEEDS IDENTIFIED	# REPORTING	% REPORTING ^b	RANK
General Information/Orientation to Brain Impairments	4,769	68.25%	1
Emotional Support	4,045	57.9%	2
Respite Care (for the caregiver) ^c	3,721	53.25%	3
Direct Care of the Adult With Brain Impairment ^d	1,749	25%	4
Financial Advice/Aid	1,454	20.8%	5
Behavior Management Advice	1,183	16.9%	6
Legal Information/Advice	1,164	16.7%	7
Other	1,071	15.3%	8
Placement Help	492	7%	9
Diagnostic/Medical Advice	310	4.4%	10
Rehabilitation	74	1.1%	11
Public Policy/Research	15	0.2%	12

a Needs identified are based on responses from 6,988 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
 07/01/2004 through 06/30/2005

NEEDS IDENTIFIED	# REPORTING	% REPORTING ^b	RANK
General Information/Orientation to Brain Impairments	677	44.3%	1
Respite Care (for the caregiver) ^c	182	11.9%	2
Other	97	6.4%	3
Emotional Support	60	3.9%	4
Direct Care of the Adult with Brain Impairment ^d	52	3.4%	5
Legal Information/Advice	50	3.3%	6
Financial Advice/Aid	24	1.6%	7
Training	17	1.1%	8
Placement Help	12	0.8%	9
Diagnostic/Medical Advice	8	0.5%	10
Behavior Management Advice	4	0.3%	11
Public Policy/Research	3	0.2%	12
Rehabilitation	1	0.1%	13

a Needs identified are based on responses from 1,528 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.

TABLE 14
 CAREGIVER RESOURCE CENTERS
 COMPARISON OF CRC RESPITE VOUCHER COSTS
 AND SKILLED NURSING FACILITY (SNF) COSTS
 07/01/2004 THROUGH 06/30/2005

<i>Service</i>	Average Cost per Client per Month	Average Cost per Client per Year
CRC Respite (Voucher)	\$141 ^a	\$1,695
Skilled Nursing Facility: Medi-Cal	\$3,797 ^b	\$45,569
Skilled Nursing Facility: Private Pay	\$4,477 ^c	\$53,724

a Based on total expenditures and family client caseload figures for CRC respite voucher services for FY 2004-2005.

b Source: California Department of Health Services, Medi-Cal Policy Division, Rate Development Branch, Long-Term Care Reimbursement Unit (personal communication December 2005).

c Source: This 2004 estimate was reported by California Advocates for Nursing Home Reform (CANHR website: www.canhr.org/publications/factsheets/fs_howtochoose.htm).

CALIFORNIA'S CAREGIVER RESOURCE CENTERS

SITE DISTRIBUTION LIST

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

<i>Site Number, CRC, and Counties Served</i>	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	Michelle Nevin 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: mnevin@deloro.org Web: www.deloro.org *replaced Janet Claypoole
(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	Mary Sheridan, 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: sheridan@coastcrc.org Web: www.coastcrc.org * replaced John Gaynor

Site Number, CRC, and Counties Served	Host Agency	Program Information
(08) MOUNTAIN CRC Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity	CSU Chico Research Foundation Jeanne Thomas, Ph.D. Chair, Center Policy Board California State University, Chico Chico, CA 95929-0450 (530) 898-6171	Susanne Rossi Program Director Mountain Caregiver Resource Center 2491 Carmichael Dr., Ste. 400 Chico, CA 95928 (530) 898-5925 (800) 955-0878 (regional) FAX (530) 898-4870 E-Mail: smrossi@csuchico.edu Web: www.caregiverresources.org
(09) VALLEY CRC Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, Tuolumne	Valley Caregiver Resource Center Chris Morse President, Board of Directors 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154	Margery Minney Executive Director Valley Caregiver Resource Center 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154 (800) 541-8614 (regional) FAX (559) 224-9179 E-Mail: mminney@valleycrc.org Web: www.valleycrc.org
(10) DEL MAR CRC Monterey, San Benito, Santa Cruz	Health Projects Center John O'Brien President, Board of Directors 736 Chestnut Ave., Suite F Santa Cruz, CA 95060 (831) 459-6639	Steve Lustgarden, Acting 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: steve@hpcn.org Web: www.hpcn.org * replaced Robert Phillips
(11) ORANGE CRC Orange	Saint Jude Medical Center Barry Ross Vice President, Healthy Communities 101 East Valencia Mesa Drive Fullerton, CA 92835 (714) 992-3000	Claudia Ellano Program Director Orange Caregiver Resource Center 251 East Imperial Hwy., Suite 460 Fullerton, CA 92835-1063 (714) 578-8670 (800) 543-8312 (regional) FAX (714) 870-9708 E-Mail: cellano@stjoe.org Web: www.caregiveroc.org

**STATEWIDE
RESOURCES
CONSULTANT**

Family Caregiver Alliance
Kathleen Kelly
Executive Director
180 Montgomery St.,
Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
E-Mail: kkelly@caregiver.org

Kathleen Kelly
Project Manager
Statewide Resources Consultant
180 Montgomery, Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106 (statewide)
FAX (415) 434-3508
E-Mail: kkelly@caregiver.org
Web: www.caregiver.org

**CALIFORNIA
DEPARTMENT OF
MENTAL HEALTH**

Jane Laciste
TBI/CRC Program Administrator
1600 9th Street, RM 130
Sacramento, CA 95814
(916) 654-3529
FAX (916) 653-0200
E-Mail: jane.laciste@dmh.ca.gov
Web: www.dmh.cahwnet.gov

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,ⁱ 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.ⁱⁱ 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.ⁱⁱⁱ

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 Disorders^{iv}

DIAGNOSIS/CAUSE	PEOPLE DIAGNOSED ANNUALLY
Alzheimer's Disease	360,000 ^v
Amyotrophic Lateral Sclerosis	5,000 ^{vi}
Brain Tumor	36,400 ^{vii}
Epilepsy	134,000 ^{viii}
HIV (AIDS) Dementia	1,196 ^{ix}
Huntington's Disease	N/A
Multiple Sclerosis	10,400 ^x
Parkinson's Disease	50,000 ^{xi}
Stroke	750,000 ^{xii}
Traumatic Brain Injury	85,000 ^{xiii}
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 ^{xiv}	4,000,000 ^{xv}
Amyotrophic Lateral Sclerosis	20,000 ^{xvi}	30,000 ^{xvii}
Brain Tumor	350,000 ^{xviii}	350,000 ^{xix}
Epilepsy	1,984,000 ^{xx}	2,000,000 ^{xxi}
HIV Encephalopathy (dementia)	14,537 ^{xxii}	58,150 ^{xxiii}
Huntington's Disease	30,000 ^{xxiv}	30,000 ^{xxv}
Multiple Sclerosis	250,000 ^{xxvi}	350,000 ^{xxvii}
Parkinson's Disease	500,000 ^{xxviii}	1,500,000 ^{xxix}
Stroke	4,000,000 ^{xxx}	4,600,000 ^{xxxI}
Traumatic Brain Injury	2,500,000 ^{xxxii}	5,300,000 ^{xxxiii}
TOTAL PREVALENCE	11,986,537	18,218,150

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

Table 3: Select Population Characteristics: United States and California

	United States	California
Total Population	284,796,887 ^{xxxiv}	34,501,130 ^{xxxv}
Total Population 18+	211,604,087 ^{xxxvi}	25,082,322 ^{xxxvii}
Total Households	105,480,101 ^{xxxviii}	11,502,870 ^{xxxix}
Total Estimated Adults with Brain Impairment		
a. Low Estimate	11,968,537 ^{xi}	1,418,681 ^{xi}
b. High Estimate	18,218,150 ^{xlii}	2,159,474 ^{xliii}
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 ^{xliv}		
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.

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- ⁱ 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/>
- ⁱⁱ 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
- ⁱⁱⁱ 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
- ^{iv} 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.
- ^v 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.
- ^{vi} 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
- ^{vii} 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.)
- ^{viii} 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.)
- ^{ix} Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(No. 2): 18.
- ^x 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.
- ^{xi} American Parkinson's Disease Association. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>
- ^{xii} National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from http://www.stroke.org/pages/press_disease.cfm
- ^{xiii} 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.)
- ^{xiv} 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.
- ^{xv} 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>
- ^{xvi} 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
- ^{xvii} 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>
- ^{xviii} 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.)
- ^{xix} Ibid.
- ^{xx} 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.)
- ^{xxi} 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
- ^{xxii} 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.)
- ^{xxiii} 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.)
- ^{xxiv} 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
- ^{xxv} Ibid.
- ^{xxvi} 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
- ^{xxvii} Ibid.
- ^{xxviii} 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

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- ^{xxix} National Parkinson Foundation. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>
- ^{xxx} National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from http://www.stroke.org/pages/press_disease.cfm
- ^{xxxi} American Heart Association. (2002). *2002 heart and stroke statistical update*. Retrieved October 22, 2002 from <http://www.americanheart.org/statistics/>
- ^{xxxii} 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.)
- ^{xxxiii} 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>
- ^{xxxiv} 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.)
- ^{xxxv} Ibid.
- ^{xxxvi} Ibid.
- ^{xxxvii} Ibid.
- ^{xxxviii} Ibid.
- ^{xxxix} Ibid.
- ^{xl} See Table 2.
- ^{xli} These estimates are based on the percentage of population age 18+ years residing in CA.
- ^{xlii} See Table 2.
- ^{xliii} These estimates are based on the percentage of population age 18+ years residing in CA.
- ^{xliv} Assumes one brain impaired individual per household.