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

CALIFORNIA
Caregiver
Resource
Centers

July 1, 2006 through June 30, 2007

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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

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EXECUTIVE SUMMARY

The year 2006 marked the 22nd 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-point-of-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 260,000 California families, helping them give long-term care at home.

A caregiver's life changes forever when a loved one falls 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, 2006, to June 30, 2007 (FY 2006-07). 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 cognitively impaired persons and their families are identified and addressed with appropriate programs and services.

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[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.

The total amount of the contracts awarded in FY 2006-07 to the 11 CRCs and the SRC was $11,747,013. This contract amount has remained unchanged for the past four years.

During FY 2006-07, 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—those caring for the frail elderly or for someone with a chronic illness not involving cognitive impairment—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]

Among CRC system highlights for the last year are the following:

> 6,783 new clients completed the intake process; more than half of those completing intake (55 percent) went on to complete a formal assessment and receive a care plan for CRC services within the fiscal year.
>
> 13,576 family caregivers were part of the CRCs' caseload (counting only those caregivers who received an assessment after intake); fewer cases were closed due to out-of-home placement than in the previous two years—506 in FY 2006-07 versus 523 in FY 2005-06 and 531 in FY 2004-05.
>
> 13,561 clients received family consultations and 8,024 clients had reassessments, including 4,249 due to changes of status.
>
> 16,838 individuals received one or more CRC services, including 1,628 families who received respite assistance.
>
> The 11 CRCs expended $2,809,412 for respite care services. Annualized, the average cost per family using respite care was $1,726.
>
> The average client wait-time for CRC respite assistance decreased by two months (since last year) to a 24-month wait; at the end of FY 2006-07, 5,958 family caregivers were on respite waiting lists at CRCs in California.

CRC statewide assessment data shows that for FY 2006-07:[4]

> The typical (median) family caregiver that the CRC system serves is 58 years old (average age is 59) and cares for someone who is 80. Many caregivers (47

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

[4] Data are from the CRC Intake data set and the Uniform Assessment Database FY2006-2007. See the Methodology section for more detailed information.

percent) are age 60 or older; 21 percent are between the ages of 36 and 50; and 17 percent are age 75 or older. While the average age of caregivers has declined slightly over the last 15 years (from age 61 in 1990 to age 59 in FY 2006-07), the age of care recipients has increased steadily (from age 70 in 1990 to age 77 in FY 2006-07).

Caregivers seeking assistance are increasingly diverse ethnically. The non-White proportion of CRC clients was 31 percent in FY 2006-07—15 percent Hispanic, 8 percent African American, 6 percent 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 (25 percent) of the care recipient. Also, the majority of care recipients are female (59 percent).

Nearly half (49 percent) of caregivers under the age of 65 work either full time (31 percent) or part time (18 percent).

Three-fifths (58 percent) of care receivers are unable to manage three to five of their own daily living activities (such as bathing, eating and dressing); three quarters (75 percent) cannot be left alone and more than half (52 percent) are incontinent (loss of bowel and/or bladder control).

The caregiver's average tenure in the caregiving role is 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 46 years.

Caregivers provide an average of 12.7 hours of care per day, seven days per week—much more than a typical full-time job.

Caregivers receive an average of only 1.6 hours of help per day from family members or friends. One in five (19 percent) reports getting no help. Another 65 percent say that they receive "far less" or "somewhat less" help than they need from family or friends.

Three-fifths (61 percent) of caregivers report experiencing "anxiety or depression" in the past 12 months. Based on standard measures, 41 percent have clinically significant symptoms of depression and 50 percent have high burden levels.

At the time of first contact with the CRCs, the most frequently expressed need among caregivers was for general information, followed by emotional support and respite**.** For caregivers who have been assessed and are clients of the CRC system, a different pattern emerges: **Respite care is the most frequently identified unmet need, followed by emotional support and basic information.** In some difficult cases, family caregivers may not be able 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. Promote public policy that advances the consumer-directed model of care for caregivers and care receivers.

2. Promote policies that recognize and assess family caregivers as part of transitional (hospital/SNF to home) and long-term supports and services, as well as care planning.

3. Utilize the CRC client record system to monitor and promote targeted outcomes for caregivers. Additional work is required for a full implementation of the uniform client record tool across the CRC system.

4. Improve assistance to working and isolated caregivers via technology. For example, increase the number of caregivers using the Internet-based Link2Care program and tele-caregiving workshops.

5. Explore the idea of establishing liaisons with the private sector to provide caregiving resources to caregivers who work outside the home.

6. Work cohesively with statewide groups addressing the need for appropriate and affordable long-term support and services 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 support and services.

7. Identify viable program options for traumatic brain injury caregivers and their loved ones.

8. Carry out CRC research to: (a) measure and analyze the impact of cognitive disorders on family and caregiver well being; (b) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers; and (c) evaluate new modes of communication, support, and education for caregiver families.

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

10. Seek opportunities to introduce the California Family Caregiver Policy Framework into the development and implementation of public policy for health care and social services.

11. Consider new research findings on caregiver assessment and use these to review the current CRC tool and practices.

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.**[5] Caregivers of cognitively impaired adults have special needs beyond the basic information, emotional support and occasional respite from ongoing demands that almost all caregivers want. Such debilitating conditions as 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 and changes in behavior and personality, 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:

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[5] Center for the Advanced Study of Aging Services. (January 2003). Scharlach, A., Sirotnick, B. Bockman, S. Neiman, M. Ruiz, C. Dal Santo, T. *A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers*. 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 impairments.
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, 2006, through June 30, 2007.

METHODOLOGY

Six sources of information were 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; (5) the CRC 2006-07 Satisfaction Survey; and (6) the DANIC uniform client record system.

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 2006-07 Satisfaction Survey***, conducted by the SRC, provides data from a computer-generated sample of caregivers served by all CRCs between January and March 2007. Of the 4,259 caregivers selected to complete the survey, 1,497 responded—a 35% 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 statewide and in Vietnamese also for Orange County) to clients in the sample; caregivers returned the anonymous surveys directly to the SRC, which analyzed the data for the California Department of Mental Health (DMH) and shared aggregate and site-specific results with each CRC.

6. ***DANIC***, a uniform client record system, combines the functionality of the CRC Services Automation system and the uniform caregiver assessment database. DANIC implementation began at Bay Area CRC on November 1, 2005; at this CRC DANIC fully replaced Services Automation and the Uniform Caregiver Assessment database on April 1, 2006. DMH is evaluating the viability of implementing this uniform client record system at every CRC throughout the state. **The statewide implementation of a uniform record system would allow distributed data entry of client records at each CRC, while centralizing storage of all client data collected.**

COST AND AMOUNT OF SERVICE PROVIDED

In FY 2006-07, the total contract award from DMH to the 11 CRCs and the SRC was $11,747,013 ($10,872,227 to the CRCs and $874,786 to the SRC). (See Appendix A, Site Distribution List, for a listing of site names, host agencies, and counties covered by the CRCs.)

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 26 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 2006-07 Satisfaction Survey shows how the CRC services are regarded:

> “Your services were above and beyond what I ever dreamed of and your staff was wonderful. Your help helped me soooo much. I had no idea what my husband’s Alzheimer’s disease was like and you helped me through it all. Thank you so much. God Bless You All!!!!”
>
> “You have a great organization and the best help you can offer is helping pay for the respite care. These three months have been a blessing to have some help but can’t imagine now not having it because we can’t afford it. It’s amazing what a big difference a few hours a week make. Thank you.”
>
> “Without the help of DMCRC [Del Mar Caregiver Resource Center], my mother would have been unable to stay in her home for as long as she has. The emotional, financial support has been very helpful to me, her daughter and to our whole family. We have been helped tremendously by being a part of DMCRC.”
>
> “The 5-star support team has become my family. I learn new things every week and can care for my husband much better with less anger on both of our parts.”
>
> “If it’s not broken, don’t fix or change it! I am very happy with my caregiver resource center. I couldn’t ask for a better staff! From the classes, to the instructors, the support group facilitators, the administrative office help all do a superb job. I feel like you have saved my life both physically and emotionally. My husband is getting much better care since I have taken the classes. I feel great because of my expanded knowledge and skills and a great support group.”

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[6] 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; and

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 Statewide Resources Consultant functions. DMH contracts with Family Caregiver Alliance to serve as 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 and 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;

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[6] 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.

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.

Key highlights of the Statewide Resources Consultant's activities in Fiscal Year 2006-07 are:

Development and dissemination of two new fact sheets, "Caregiver Health" and "California Caregivers: A Profile," and three revisions to existing fact sheets.

Dissemination of "Caregivers at Risk: A Public Health Concern," the first in the new *Caregiving in California Issue Paper* series.

Development and dissemination of online and print newsletters that reach a combined subscription of nearly 29,000 consumers and professionals. Dissemination for the year included 12 issues of *California Caregiver*; 22 issues of *Caregiving Policy Digest*; and 3 issues of *Update*.

Development and coordination of capacity-building trainings for CRC staff . Topics covered included: telephone-delivered psychoeducational classes, group facilitation, ambiguous loss, and CRC system protocols on client charting ,data documentation and suicide prevention.

Consolidation of data across CRC system into standardized reports on quarterly and annual basis.

Preparation of testimony for legislative committees and commissions; participation in state and national conferences, as well as a wide variety of advisory committees

Facilitation of four statewide telephone conference workshops for consumers, including one targeted for Spanish-speaking caregivers.

Utilization of telemedicine networks to train caregivers through rural health clinics and hospitals in northeastern California.

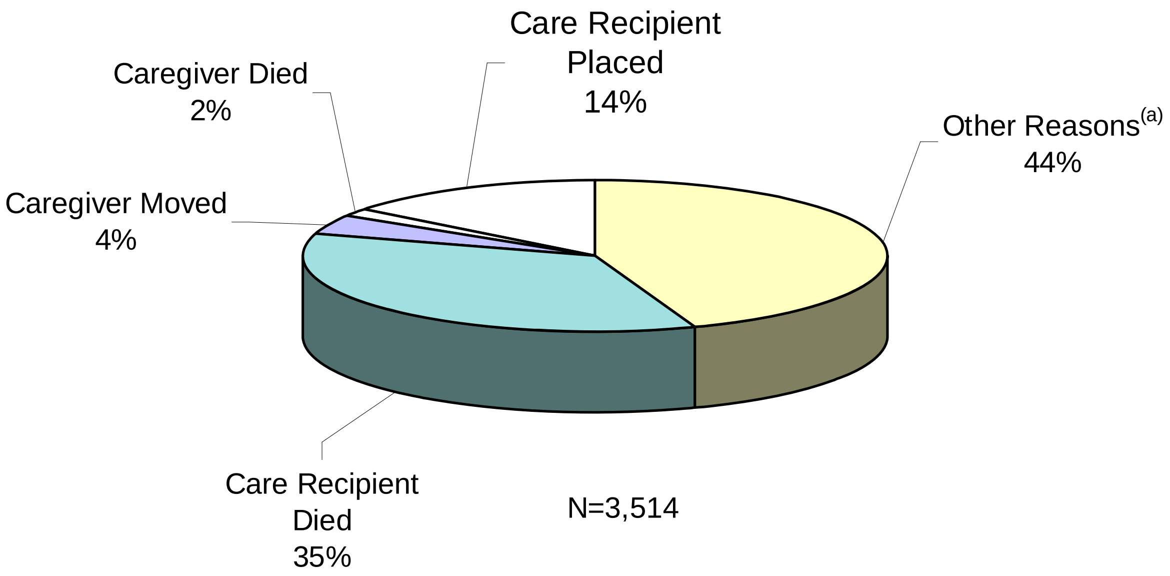
Development of an ethics and policy framework to promote inclusion of caregivers in public policy.

Cost and Service Findings

In FY 2006-07, 16,838 family caregivers received at least one CRC service, including intake, assessment, family consultation, 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 20.4 hours. Excluding respite, the average was 5.6 hours. (See Table 1).
>
> The number of active clients—clients who had been assessed and were receiving services (or waiting for respite)—reached 13,576 during FY 2006-07. During the year, 3,514 cases were closed. About one-third (35 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).

Figure 1. Percent of Closed Cases by Reason, FY 2006-07



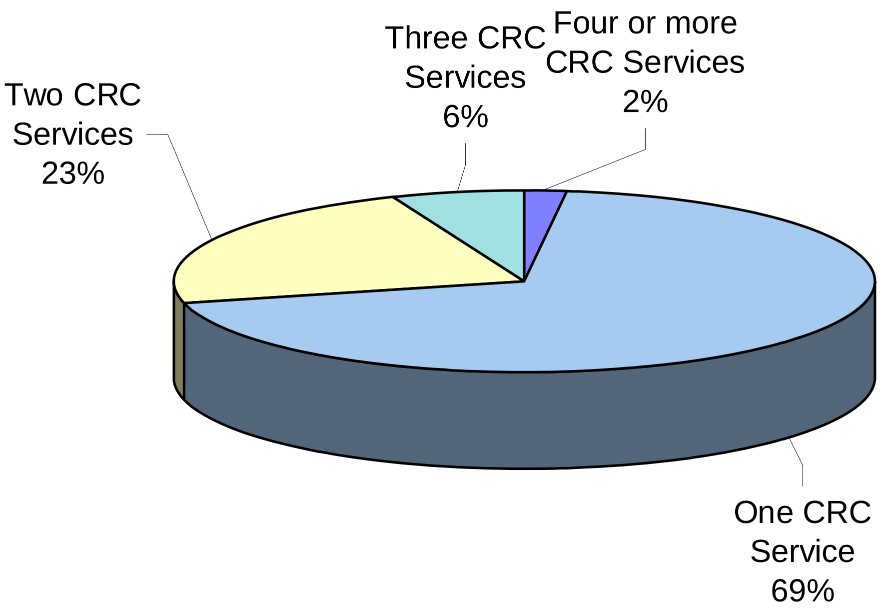
[a] "Other Reasons" include families who declined further services or who could not be reached for a reassessment after multiple contacts.

In all, 6,783 new family caregivers completed the intake process; 3,726 went on to have full, usually in-home, assessments of their needs. The CRCs provided 8,024 reassessments (full reassessments for 3,775 caregivers and updates due to status change for 4,249) (see Table 3).

The most-used core services were family consultations (used by 13,561 families), respite care (1,628), support groups (1,107), and psychoeducational groups (679). The average length of time for a family consultation was 2.7 hours; and the average amount of respite per user was 138.1 hours. The average time spent attending a support group was 8.9 hours. (See Tables 3 and 5).

The majority of family caregivers (69 percent) used only one service beyond intake and assessment in FY 2006-07; just 8 percent of family clients used three or more services (see Figure 2).

Figure 2. Family Caregivers Receiving Services from CRCs by Number of Services, FY 2006-07[a]



N = 15,198

[a] Based on data from 11 CRCs. Includes CRC “core” services only (family consultation, counseling, psychoeducational groups, support groups, legal consultation and respite). The Link2Care online system, access services (intake, assessment and reassessment), family-focused education and wait lists are excluded.

Overall, among all services tracked by hours, respite care had by far the highest usage at 224,819 hours. Among the respite care options (in-home, daycare, out-of home facility care), in-home care was used most: 164,699 hours (see Table 4).

Ten CRCs offered legal/financial consultation and 361 caregivers took advantage of this service. The average time per consultation for each caregiver was 1.1 hours (see Tables 3 and 5).

In all, 289 caregivers received individual counseling this year, slightly up from 278 last year. The average time spent in counseling was 4.8 hours, compared to last year’s average of 4.5 hours (see Tables 3 and 5).

Psychoeducational groups offered by 10 CRCs served 679 caregivers this year (slightly more than last year’s 629). The average time a caregiver spent in such a group was 10.5 hours. In all, over 300 group sessions were held throughout the state during the year. Examples of the topics are: “Taking Care of You—Powerful Tools for Caregiving,” “It Takes Two: A Refreshing Approach to Understanding Dementia Behavior” and “Controlling Your Frustrations.” "It Takes Two…" was successfully offered for the first time by phone in rural northern California.

Across the state, over 300 different family-focused education and training events were held (in addition to the psychoeducational groups). The topics were diverse. Among the most popular were basic caregiving skills; long-term care planning, including legal issues; coping and stress management; and communication and behavior management with dementia. A sampling of specialized family-related topics include: “Approaching End-of-life Decisions,” “Understanding Memory Impairment & Family Dynamics,” “Caregiver Burnout,” and “Caring for the Caregiver.” The combined attendance for these events was 21,874; this number may represent a duplicated count since some caregivers may have attended more than one event.

In FY 2006-07, 1,698 caregivers participated in Link2Care, a 15 percent increase over last year (1,471). This web-based support and education program was available to caregivers through all 11 CRCs. Approximately 90 percent of the participants are subscribed to the online support group. The program's peer support group facilitator continues to foster an effective peer-to-peer network within the 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 2006-07, 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. The findings section that follows provides descriptive statistics about the caregivers and care receivers served by the CRCs in FY 2006-07 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 2006-07 Satisfaction Survey completed during the year provide this information.

Service Demand Findings

Key findings about service demand from intake information and the assessment database follow.

Caregivers

The average caregiver served by California's CRC system is a 59-year-old woman who has been caring for her father or husband with Alzheimer's disease for three to four years. The greatest caregiver needs, as reported during intake, are for general information/orientation (66 percent), emotional support (51 percent), respite care (48 percent) and direct care of the adult with brain impairment (29 percent). Other expressed needs are for help in managing the care receiver’s behavioral problems (20 percent) financial advice and aid (13 percent), and legal information (13 percent) (see Table 11).

> Caregivers range in age from 17 to 100 years, with the average age of 59. The largest group (47 percent) is age 60 or older, with 17 percent 75 years or older. About one in four (21 percent) is between 36 and 50 years old.
>
> Most often, the caregiver is an adult child (47 percent) of the care receiver, but about one in three (35 percent) is the spouse and one in eleven (9 percent) has another (non-family) relationship with the care receiver. Caregivers served by the CRC system are likely to identify themselves as the "primary" caregiver (88 percent) and to live with the care receiver (71 percent). This profile has shifted over the last fifteen years. In 1990, the distribution of relationships was spouse (55 percent), daughter (16 percent) and other (29 percent), a category that

included sons, other relatives and non-relatives. A much higher proportion lived with the care receiver (87 percent).

The majority of family caregivers served by the CRCs are White (69 percent). However, CRC caregivers are increasingly diverse. Caregivers served report their ethnicity as Hispanic (15 percent), African American (8 percent), Asian/Pacific Islander (6 percent) and other ethnic groups (8 percent). In 1990, the ethnic distribution was White (88 percent), Hispanic (4 percent), African American (5 percent) and other (3 percent).

Nearly half (49 percent) of caregivers under the age of 65 also work outside the home, full time (31 percent) or part time (18 percent). In 1990, 28 percent of caregivers were employed outside of the home.

Depression is a significant problem for family caregivers. More than four in ten (43 percent) of CRC family caregivers show clinical symptoms of depression.[7] Caregivers generally report high stress due to their caregiving situation, regardless of their care receiver's specific diagnosis. Three-fifths (61 percent) of caregivers self-report feeling "depressed" or "anxious." Overall, 54 percent of caregivers score in the "high burden" range on the Adapted Zarit Interview in the caregiver assessment.[8]

About one third (28 percent) of caregivers say their physical health is now worse than it was six months before. One-third of caregivers (32 percent) report their overall health as "fair" or "poor." The leading health problems among caregivers are high blood pressure (31 percent), back and neck problems (27 percent), blood/liver/kidney problems (27 percent), arthritis (26 percent), high cholesterol (25 percent) and sleep disturbances (21 percent).

Caregivers provide an average of 89 hours of care each week—about 12.7 hours/day, seven days a week. They receive little help from others— the average caregiver gets only 11.1 hours a week of unpaid help from friends, family, or volunteers, and half (50 percent) of caregivers report receiving no unpaid help at all. The average amount of paid help caregivers report receiving is 9.5 hours a week.

Care Receivers

Care receivers range in age from 18 to 103 years old, with an average age of 77 and a median age of 80. Ninety percent of care receivers are age 60 or older. The majority (84 percent) are at least 65 years of age; 69 percent are 75 years of age and older; and nearly a third (30 percent) are at least age 85. In 1990, the average age of care receivers was 70.

More care receivers are female (59 percent). In contrast, in 1990, most care receivers were male (60 percent).

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

[8] As evidenced by scores of 17 or higher on the scale for the Adapted Zarit Interview.

Only a few care receivers live alone (15 percent) or in nursing homes (2 percent) when the caregiver first contacts a CRC for assistance.

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 estimated at $74,801 for a family of four in 2006.[9]

Nearly two-thirds (64 percent) of care receivers have a degenerative illness, principally Alzheimer's disease (31 percent), but also Parkinson's disease (4 percent), Huntington's disease (1 percent), and other dementias and/or degenerative diseases (28 percent). Of the remaining care receivers, 27 percent had suffered a stroke, 6 percent are traumatic brain injury survivors and 3 percent have brain tumors or other non-degenerative disorders. The vast majority of care receivers (84 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.

Almost half (49 percent) of care receivers experienced the onset of their disease /disorder less than two years ago; 10 percent have lived with a cognitive disease/disorder for 10 years or longer.

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 managing money, taking medications, performing household chores, preparing meals, requiring supervision, bathing/showering 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 60 percent 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
- Appearing sad or depressed.

Of the care receiver's behavioral problems, the following were the most bothersome or upsetting to their caregivers:

- Engaging in behavior that is potentially dangerous to self or others
- Threats to hurt oneself
- Threats to hurt others
- Acting aggressively toward others verbally

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[9] U.S. Census Bureau, 2005. From *http://www.census.gov/hhes/www/income/medincsizeandstate.html*

- Commenting about death of self or others.

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 2006-07 for respite care through the CRCs has grown to 5,958 (up from 5,541 in FY 2005-06). The average waiting time is two years (24 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, through adult day care or out-of-home facility care. 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.[10][10]
>
> 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.
>
> 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.

Caregivers also need additional affordable counseling services—both extended and brief (six one-hour sessions)—and more 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 (i.e. caregivers under age 60) and those caring for a younger adult cannot access needed

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[10] 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.

support from the AAAs. In addition, families who use In-Home Supportive Services (IHSS) are ineligible for respite from the CRCs except in a very limited number of situations. 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 (TBI) 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 survivors—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.
>
> A 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. For example, there is an unmet need for Spanish-language support groups in the Los Angeles area.

Caregivers also continue to have great difficulty accessing adequate care for their loved ones' medical and dental problems.

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

Caregiver Satisfaction with CRC Services

The CRC 2006-07 Satisfaction Survey queried 4,259 randomly selected family caregiver clients and 1,497 responded (a response rate of 35 percent). Respondents had received services from the CRCs for varying lengths of time: Almost two-thirds (62 percent) indicated that they had been associated with their local CRC for "over 12 months." Two-thirds (66 percent) were receiving services at the time of the survey. Almost all caregivers:

> Said their satisfaction with the overall quality of the services received from their local CRC met, was above, or was far above their expectations (95 percent)
>
> Said they would recommend the CRC to others (97 percent).

Caregivers also were nearly unanimous in saying:

> Staff showed respect for their time and were courteous and helpful (98 percent).
>
> Appropriate questions were asked to determine the caregiver's needs (97 percent).

Caregivers were asked, “Thinking of your experience over the last 12 months, was the service [this] CRC provided or helped you to pay for helpful to you in your caregiving situation? (Check N/A for any services not used).” The great majority of caregivers found the services that they had used to have been helpful. Following is a list of these services, the number of caregivers reporting use of them and the percentage of service users that found the service helpful:

- Written information: 94 percent (1022 responses)
- Education programs: 93 percent (508 responses)
- Caregiver consultations: 95 percent (873 responses)
- Individual counseling: 90 percent (299 responses)
- Support groups: 93 percent (580 responses)
- Legal/financial consultations: 90 percent (448 responses)
- Link2Care: 88 percent (266 responses)

Among those who used respite services:

- 90 percent (340 responses) found adult daycare services provided helpful.
- 92 percent (626 responses) found in-home respite received helpful.
- 83 percent (268 responses) found out-of-home respite (nursing home and assisted living) helpful.
- 90 percent (268 responses) found caregiver retreats helpful.

PROGRAM IMPACT

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

As to the program’s role in deterring institutionalization, the characteristics of the care receivers who are being cared for at home provide clear evidence. 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.[11]

A recent study of IHSS users focused on those who were most likely to have a long-term placement in a nursing facility.[12] Among the characteristics leading to placement were dementia, Parkinson’s disease or stroke (which, respectively, increased chance of institutionalization by 163 percent, 78 percent and 52 percent); requiring assistance with

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[11] Williams, Shirley. *Project Overview: Nursing Facility Eligibility*. From www.ltci.ucla.edu/toolkit/nfcertifiability.ppt

[12] 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.ltci.ucla.edu

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 506 care receivers were placed in FY 2006-07, or 4 percent of the CRC caseload. By helping caregivers the CRC system appears to be deterring institutionalization of care receivers.

The CRC 2006-07 Caregiver 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.

> Nearly all respondents (90 percent) strongly agreed or agreed that they were better able to manage the care of the care receiver as a result of receiving CRC services.
>
> Nearly all respondents (96 percent) strongly agreed or agreed that as a result of receiving services they have an increased knowledge and awareness of community resources to help caregivers.
>
> Nearly all respondents (92 percent) strongly agreed or agreed that they are taking better care of their own health (both physically and mentally) as a result of working with a CRC.

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 continue to take leadership roles and collaborate at the state and local levels to increase understanding about the needs of family caregivers and deploy resources to help them. Among their leadership roles in the 2006-07 fiscal year are the following:

- Members of Boards and Advisory Committees of non profit community agencies, such as SF Adult Day Care, Stroke Education Committee of the American Heart Association, Planning for Elders in the Center City (San Francisco, Bay Area CRC).
- Chair of the Caregiver Coalition (service provider and consumer network), sponsored by San Diego County's AAA. Participation in this coalition resulted in co-sponsorship and development of several community education events specifically targeted to caregivers. (Southern CRC).

- Active participants in Senior Roundtables for contracted counties: SF, Marin, Contra Costa, Alameda (Bay Area CRC).
- Leader of LACRC- Villa Esperanza Services partnership that developed a series of 12 presentations on issues related to caring for a brain impaired adult. Villa Esperanza has also opened up their Adult Day Health Services to include adults in the community who have been recently diagnosed with a brain impairing condition (Los Angeles CRC).
- Participants in several activities in conjunction with the Imperial County AAA's "Info. Van" resulting in outreach to many caregivers in Imperial County (Southern CRC).
- Actively participants in Long Term Care Integration Project meetings sponsored by San Diego County's AAA (Southern CRC).
- Member of Mendocino County Health Planning Council, Advisory Council to the Mendocino County Board of Supervisors (Redwood CRC).
- President of the Association of Caregiver Resource Centers as of July 1, 2006 (Los Angeles CRC).
- Actively participates on the senior coalitions for Tri-County Seniors, Alameda County Senior Services, San Mateo Caregiving Coalition (Bay Area CRC).
- Recipient of certificate from the Area 4 Agency on Aging Governing Board for outreach activities and education and training during Older American's Month (Del Oro CRC).
- Educator of volunteers at Hospice of the Foothills in Nevada County on Caregiver Issues and Alzheimer's disease (Del Oro CRC).
- Sponsor of series of community presentations in Ventura County: "Are you Ready? Are Your Parents Ready? Aging in the 21st Century" (Coast CRC).
- Co-chair/Secretary, Tehama County Elder Services Coordinating Council and Chair, Transitions Coalition (PSA2 FCSP program) (Mountain CRC).
- Participants in the Alzheimer's Foundation Coalition Merced and Fresno meetings and activities (Valley CRC).
- Serve on the Mendocino County Caregiver Cooperative and the North Coast Senior Collaborative (Redwood CRC).
- Successful fundraiser for caregiver services, obtaining support from Community Foundation of Santa Cruz County, Community Foundation of Monterey County, Harden Foundation, Barnett J. Segal Foundation and United Way of San Benito County (Del Mar CRC).
- Serve on the statewide California Coalition of Caregivers (Los Angeles CRC, Bay Area CRC, SRC).
- Participant in Senior Summit with Assemblywoman Lynne Daucher and organizer of Caregiver Advocate Network to prepare for spring legislative visits (CRC of Orange).
- Host for monthly education series, "Mastering Caregiving Through Education and Awareness," supported through National Family Caregiver Support Program grant funds from both Riverside and San Bernardino Counties (Inland CRC).
- Creator of new model of delivering support groups on short-term, theme oriented basis, using a video education series as the basis of the training and group dynamics

and sharing to engage the group in a supportive, cohesive group atmosphere (Inland CRC).

The CRCs this year had considerable success in engaging the media to educate the community about caregiving and issues important to caregivers: Examples of coverage include:

- Information for an article in the *San Diego Union Tribune* on “Aging in Place” (Southern CRC).
- Local Santa Barbara televised presentation: “Santa Barbara Matters – Caregiving” – 8 repeats of this program (Coast CRC).
- Televised presentation: “Solutions for Senior Care” in Ventura county – three repeats of this program (Coast CRC).
- Interview on CNN TV, article on Long Term Caregiving in *San Francisco Chronicl*e, *Contra Costa Times*, *Oakland Tribune*, *San Mateo Times*, *Palo Alto Daily News*, *Tri-Valley Herald*, *Hayward Daily Review*, *Fremont Argus*; article on the Bay Area LGBT community in *Bay Area Reporter* (Bay Area CRC).
- Interviews on KABC talk radio show, “Spotlight on the Community,” Skylink TV (Chinese TV station). International Daily News, Chinese L.A.Daily News and Zhong Guo Daily News. Coverage by *Antelope Valley Press* and *Daily News*, city of La Mirada’s local newspaper, caregiver profiles in the Health Section of the *LA Times* (Los Angeles CRC).
- Press Conference conducted in Chinese on four TV Stations; six newspapers reported on event (Los Angeles CRC)
- Barstow, CA “Barstow Dispatch”(Inland CRC).
- Interviewed on KFOK Radio in Georgetown, CA on the show “Aging with Success,” Nevada County KNCO radio, Mount Shasta Herald (Genetic testing and HD, Interviewed by CSUS Journalism Student regarding AB 537 (Del Oro CRC).
- Information provided for San Diego Union Tribune “Aging in Place” article (Southern CRC).
- Feature article in Santa Barbara News Press highlighting client’s journey to care for her husband and highlighting Stroke Caregiver Support Group offered by CCRC; AARP California Update article about caregiver retreat, Thousand Oaks Council on Aging (television show), interview to “Ventura star” (newspaper) on caregiver issues, Ventura county (thousand oaks) local tv televised 3 repetitions of “solutions for senior care – a panel of experts (Coast CRC).
- Plumas Senior News—Article on Caregiving, KCHO-KFPR Radio—PSA on Caregiving, Big Valley News—Article on MCRC & Caregiver Support (Mountain CRC).
- Univision Spanish Program and Telefutura Spanish Radio 30 minute interview about VCRC Services (Valley CRC).

- Caring for the caregiver: Support networks offer relief from relentless stress, Santa Cruz Sentinel Article,**Article in The Californian, “Caregiver University Offered: Event aimed at those caring for family members.” Executive Director was interviewed, radio interviews and paid promotions to publicize Caregiver University (Del Mar CRC).

Specific leadership efforts have focused on improving caregivers’ access to health care expertise and raising awareness among employers:

- We have continued outreach to the workplace, giving series of lunch time talks to PG&E, University of California, Office of the President, USF, UCSF (Bay Area CRC).
- Collaborate with Spice of Life, an organizer of health and lifestyle expos for employers. SCRC has made an information table and staff available at several events through Spice of Life, resulting in outreach to hundreds of working caregivers (Southern CRC).
- “Thinking Outside the Box,” a lecture on Alzheimer’s disease to an expert panel for the Rosalinde and Arthur Gilbert Foundation. This meeting was to help the foundation develop its grant making strategy in the area of Alzheimer’s disease (Los Angeles CRC, Director).
- Presented at the Chronic Care conference on “Integrating Family Caregivers into Care” The agencies involved are: The County of Los Angeles Department of Health Services, LA Care Health Plan, California Association of Physician Groups, Partners in Care Foundation, Kaiser Permanente and The Community Clinic Association of Los Angeles County (Los Angeles CRC, Director).
- Serve on the Ethics Committee, Alta-Bates Summit Medical Center (Bay Area CRC).
- Numerous high profile events highlighted the importance of using public and private resources to benefit caregivers. Examples of these events include:
- Serve on the Alameda County Health Taskforce (Bay Area CRC).
- Redding staff worked intensely on the October 4th Rural Family Caregiver Forum in helping make it so successful (Mountain CRC).
- Delivered a series of community presentations in Ventura and San Luis Obispo County's titled, *"Services for Family Caregivers", "Learn About Your Options for Care"* , "*Are you Ready? Are Your Parents Ready? Aging in the 21st Century"* (Coast CRC).
- Actively participate on the Sacramento and Sutter Commission on Aging (Del Oro CRC).

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

At the local level, consistent advocacy for caregivers continued through regular communication with local legislators and their district office staff and involvement on an array of planning committees and councils (such as mental health for older adults, adult about prevention, senior services networks and roundtables, Alzheimer’s Association groups and AA advisory councils across the state). The CRCs also focus their advocacy on specific emerging issues and caregivers with unique needs. For example:

- All CRC staff meet with legislators in their district offices on a regular basis to raise the voice of family caregivers on the agenda of the elected officials.
- Planned presentation to the Women's Caucus in August and worked on the conference to be held in Sacramento on February 5, 2008 in conjunction with the Women's Caucus (Southern CRC, Director).
- Advocated for family caregivers with local community groups including: Latino Partnership, RWJ Foundation, SF, LGBT Advisory Committee for the San Francisco Long-Term Care Task Force, Marin County CASS, Keith Carson Caregiver Coalition (Bay Area CRC).
- Sonoma County "Making the Link" committee, a federally funded program to link caregivers to local resources through their physicians (Redwood CRC, Director).
- Testified at API Roundtable for AAA on caregiving Oct 5, 2006 (Los Angeles CRC, Director).
- Testified at Commission on the Status of Women Public Hearings September 20, 2006, Los Angeles hearing (Los Angeles CRC, Director).
- California Planning Mtg. related to caregivers' need (with Bill Novelli, President of AARP(Los Angeles CRC, staff).
- Member of the Work and Family Coalition which helps educate state and local legislators as well as state departments (EDD) on family caregiver issues and concerns. Donna serves as a CRC contact with EDD on paid family leave issues and ways to work with other state departments (Los Angeles CRC, Director).
- Set up meetings between LACRC, Alzheimer's Association and Partners in Care to develop a model program for caregiver services in Los Angeles that reduces fragmentation (Los Angeles CRC, Director) .

  Provided input to the City AAA area plan for caregiving until 2015 (Los Angeles CRC).
- Attended meeting with Allison Ruff, staff member to Patty Berg regarding the ACCRC and language within the previous AB2014 (Del Oro CRC, Director).

- Attended the Master Plan on Aging press conference with Patty Berg on September 27, 2006 (Del Oro CRC).
- Attended quarterly meetings of A4AA Title III E Providers to avoid duplication of service and advocate for caregiver needs (Del Oro CRC).
- Attended the public hearing on "Alzheimer's: Public Health Crisis of the 21st Century – Will California be Prepared?"(Del Oro CRC).
- CRCC Director serves on the Santa Barbara County Mental Health Older Adult work group.
- Ventura Family Consultant serves on the City of Thousand Oaks Council on Aging.
- Director and staff visited district offices of to highlight CRC system and advocate for expanded services for caregivers.
- Staff and Caregivers met with staff of Senators McClintock and Maldonado, and Assemblyman Blakeslee and Assembly members Pedra Nava (Santa Barbara & Ventura counties) and Audra Strickland (Ventura County) (Coast CRC).

- Executive Director met with State Representative John Laird to educate him and his staff about caregiver services and issues (Del Mar CRC).

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, the CRC system moved ahead in a proactive way in using the Internet to communicate across CRCs and with caregivers. Staff from the CRCs used the statewide website to access forms, policy information and new content developed by other CRCs, such as fact sheets for use by clients and as a training tool for staff. The online program, Link2Care, continues to expand as a client service and several CRCs participated in it's "Ask An Expert" component (Bay Area, Coast, Southern and Valley CRCs). In addition, the SRC developed, California Caregiver newsletter continues to grow in popularity with over 1,100 subscribes including individuals from every CRC region.

Other key developments include:

- When available, this information is regularly distributed through CRCs newsletter and through flyer distribution and e-mail notification. Distributes information through mailings (regular and e-mail), at events and at health fairs (Southern CRC)
- Link2Care is used to communicate information about educational events in San Diego and Imperial Counties (Southern CRC).
- Market Link2Care to all caregivers and continues to have a staff person who participates in the “Ask the Experts” component which ensures rural issues are considered also. Link2Care is also used as a tool to communicate education and training activities to the caregivers (Valley CRC, CRC of Orange).
- Re-enrolled in Link2Care in December 2006 which ensured statewide availability of the CRC sponsored caregiver support website and discussion group (Del Mar CRC).
- Email announcements of upcoming workshops to professionals using PDF files, email contact using Constant Contact, a web-based mail management and marketing tool (Bay Area CRC).
- Offers a caregiver (general) and an LGBT caregiver online support group (Bay Area CRC).
- Receives e-mail and phone information requests from across the state and triages these to the appropriate CRC (SRC).
- Present conference call workshops to caregivers (Bay Area CRC).
- Agency website is regularly updated and expanded including links to a variety of informative caregiver related websites (Del Oro CRC, Valley CRC).
- Updated and improved website, number of unique visitors has almost doubled over the past six months (to 4,395 in June 2007) (Del Mar CRC).
- Integrated list of clients with email address into email program to facilitate regular communication with those clients (Valley CRC).

- Del Oro continues to attend and plan outreach activities as part of the Asian Pacific/Islander Family Caregiver
- 2 CCRC Staff serve as caregiver experts for the Link2Care, "Ask An Expert" caregiver consultation service (Valley CRC).

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

Development of Danic, the uniformed client record systems introduced to the CRCs, and currently in use by Bay Area CRC/FCA, is awaiting state guidance on how to proceed. Additional resources are required for further development prior to a full statewide implementation. The Operations Manual was revised to reflect current business practices and confirm to the new standards required by the implementation of the uniform client record system. (Bay Area CRC, SRC)

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

The CRCs actively use technology in their work during the year, including email to contact clients at their convenience (e.g. outside normal business hours of the CRCs); developing digital forms to streamline data entry and reporting (Del Mar CRC); gathering information for clients on disease, chronic health conditions and resources, participating in education web conferences hosted by the SRC and by Family Caregiver Alliance National Center on Caregiving; announcing upcoming workshops to professionals using PDF files (Bay Area CRC). Staff members use the internet on a daily basis to gather information for clients on disease, chronic heath conditions, and placement resources (Del Oro CRC and others).

- All staff registered to receive California Caregiver the statewide bimonthly caregiver electronic newsletter produced by SRC. They newsletter is promoted to service providers and caregivers (Redwood CRC, Del Oro CRC, Southern CRC, Bay Area CRC)
- Continue to promote Link2Care and provide staff with monthly updates regarding this website (Southern CRC, Valley CRC, Del Oro CRC).
- Education Coordinator uses content pool on CA CRC web site for newsletter articles and DCRC website content (Del Oro CRC).
- Staff attended CRC teleconferences fall 2006 on Stroke, Dementia and Memory Impairments (All CRCs).

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

The Del Oro and Mountain CRCs collaborated with the SRC (Family Caregiver Alliance) to use technology (telephone and video conferencing) in conjunction with in-person and web methods to reach caregivers in rural communities with training and education. A grant from Bristol Myers Squibb Foundation supported this effort. Del Mar CRC, Bay

Area CRC and the SRC use Tech Soup (www.techsoup.org), a discount technology resource for non-profit organizations, for their technology needs whenever possible.

- Promote and market statewide educational teleconferences for clients and professionals (All CRCs).
- Collaboration with FCA, Mountain CRC the Northern Sierra Rural Health Network on the Rural Caregiver Grant to use technology (phone and video teleconference) to provide rural caregivers education and training.
- Kern County staff work with the Kern County Aging & Adult Services in utilizing the SAMS program. VCRC has a link to all the caregiver.org connections within the 9 county geographic areas (Valley CRC).
- The Salinas Adult School proved to be an excellent partner for a full day conference for Caregivers. Together we delivered 6 hours of education to 150 Caregivers. The partnership helped to bring new clients into the CRC system (Del Mar CRC).

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:

- Actively participate in the Dementia Care Network to plan and coordinate services and outreach programs geared to Latino caregivers (Southern CRC).
- Serve on the Latino Partnership and LGBT Partnership under the RWJ Grant to the city of San Francisco (Bay Area CRC).
- Actively worked with the VA (Veterans Affairs) on a grant submitted that expands CRC services to families of Veterans with Traumatic Brain Injury (Southern CRC).
- Maintained strategic partnership with the Asian Pacific Islander Family Caregiver Services (APIFCS) group (Del Oro CRC).
- Attended the annual Chinese New Year Festival on February 3, 2007 to reach out to this diverse population and attended the Asian Community Center Caregiver Forum in January (Del Oro CRC).
- Most CRCs employ full-time bilingual Family Consultants and other staff to communicate effectively with non or limited English speaking family caregivers. Languages spoken include Spanish, Vietnamese, Mandarin, Cantonese, Tagalog, Korean, Japanese, Mandarin/Taiwanese.
- Participated in the statewide telephone training for caregivers in Spanish on “Caring for Someone with Memory Loss” with Xavier Salazar on May 23, 2007 (All CRCs).
- Mailed approximately 3,000 brochures on CRC system sponsored telecaregiving workshops and marketed them at all events—events were Nov. 1, Nov. 8, and Nov. 15, 2006 (Valley CRC).
- Providing respite to all eligible caregivers for all Del Mar CRC education and training activities (Del Mar CRC).

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

Several CRCs individually reviewed their inventory of culturally appropriate materials and collaborated with their local communities to begin meeting this objective. For example, the Bay Area CRC maintained a resource file with articles in Spanish, Chinese and Japanese for distribution to caregivers and Del Mar CRC created a cultural competency plan. As noted earlier (Goal B, Objective 1), the CRCs shared information useful to specific cultural and language groups via the statewide CRC website maintained by the SRC.

- Responded to several requests from local community organizations to provide specific translated materials to appropriate entities.(Del Oro CRC)
- Translated additional materials into other languages (CRC of Orange).

GOAL D: Demonstrate CRC program effectiveness through caregiver outcomes.

OBJECTIVE 1: Establish Performance Outcomes Task Force.

The Performance Outcomes Task Force (POTF), established last fiscal year, is on hold pending the DANIC uniform client record system implementation action. In the interim, tracking client satisfaction remained a priority. The SRC, with the cooperation of all 11 CRCs, conducted the CRC Satisfaction Survey and distributed the results to all CRCs in June 2007.

OBJECTIVE 2: Investigate ways to use DANIC to improve caregiver outcomes by utilizing data trends.

- Danic is in operation at Bay Area CRC remaining on hold for ll other CRCs pending additional resources required for full implementation.

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

OBJECTIVE 1: Select a minimum of 3 areas in need of education/training development statewide.

- The SRC staffs a pro-active CRC Education Committee. Statewide education currently planned in psycho educational course training, and continuing education for support group leaders.
- Director of Programs and Services participates on the CRC Education Committee. Statewide education currently planned and/or needed includes leading telephone

support groups, practical tips for leading groups, facilitating family meetings and working with veterans with TBI/PTSD (Southern CRC).

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

Significant activity and innovation occurred this year with respect to caregiver retreats, building on the best practices shared during the previous year and ongoing communication among the CRCs. Examples include:

- Developed a new caregiver retreat targeting Chinese caregivers. This 48Hr! Retreat was all conducted in Mandarin with 32 caregivers. LACRC utilized a new retreat center that was closer to the Chinese community and developed new programming that provided cultural sensitivity (Los Angeles CRC).
- Expanded mini-retreat format begun in SLO county in collaboration with AARP to Ventura County (Coast CRC).
- Sponsored caregiver retreats and held one during this period. Staff and Board Members continue to review each retreat for quality and look for areas that may need improvement (Valley CRC).

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

As reported under Goal B, Objective 1, the CRCs disseminate information on culturally sensitive and competent education events through the statewide website. They also include such information in their newsletters that are mailed to caregivers in their regions and the information is distributed at health fairs and other caregiver outreach events.

OBJECTIVE 4: Hold a statewide staff development conference.

The SRC education consultant has convened the CRC Education Committee to plan a statewide meeting to be held January 2008. Southern California clinical supervisors began meeting quarterly to share best practices and establish consistency across CRCs. Northern California supervisors have continued to meet separately and periodically with their Southern California peers. The CRC Education Committee is planning regional meetings to be held in May, 2007.

- Family Consultants attended regional training for Powerful Tools in the fall. All staff participated in the CRC Suicide Protocol Training on February 27, 2007. Family Consultants participated in the Ambiguous Loss Conference Call on March 27, 2007 (Del Oro CRC and other CRCs).

- Staff development classes will be held in the north and southern regional areas in May of 2007 (Valley CRC).

RECOMMENDATIONS

Despite the progress made across the state during the past year, a great deal remains to be done to improve the situations of California's family caregivers. The following are recommendations address these needs:

1. Promote public policy that advances the consumer-directed model of care for caregivers and care receivers.

2. Promote policies that recognize and assess family caregivers as part of transitional (hospital/SNF to home) and long-term care services and support planning.

3. Utilize the CRC client record system to monitor and promote targeted outcomes for caregivers. Additional resources are required for a full implementation of the uniform client record tool across the CRC system.

4. Improve assistance to working and isolated caregivers via technology. For example, increase the number of caregivers using the Internet-based Link2Care program and tele-caregiving workshops.

5. Explore the idea of establishing liaisons with the private sector to provide caregiving resources to caregivers working outside the home.

6. 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 support and services.

7. Identify viable program options for traumatic brain injury caregivers and their loved ones.

8. Carry out CRC research to: (a) measure and analyze the impact of cognitive disorders on family and caregiver well being; (b) coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers; and (c) evaluate new modes of communication, support, and education for caregiver families.

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

10. Seek opportunities to introduce the California Family Caregiver Policy Framework into the development and implementation of public policy for health care and social services.

11. Consider new research findings on caregiver assessment and use these to review the current CRC assessment tool and practices.

TABLE 1
CAREGIVER RESOURCE CENTERS
TOTAL CLIENTS SERVED AND AVERAGE AMOUNT OF SERVICE PER CLIENT (IN HOURS)
07/01/2006 through 06/30/2007

	Total	Bay Area CRC	Redwood CRC	Los Angeles CRC	Inland CRC	Del Oro CRC	Southern CRC	Coast CRC	Mountain CRC	Valley CRC	Del Mar CRC	Orange CRC
Total # of family clients [a] Receiving at least one CRC service	16,838	2,754	1,842	2,972	955	1,435	1,612	834	808	1,797	563	1,266
Total # of family clients Receiving CRC core Services [b]	15,198	2,244	1,785	2,898	397	1,388	1,605	806	780	1,755	538	1,002
Avg. # of hours across CRC core services (excluding respite)	5.6	2.8	4.4	3.5	11.0	5.5	4.6	9.8	9.4	6.2	7.7	11.2
Avg. # of hours across CRC core services (including respite)	20.4	7.7	15.4	23.4	66.3	16.9	11.0	26.7	28.1	17.4	43.3	32.6

[a] Unduplicated count of clients using services including intake and assessment/reassessments. Excludes wait lists.

[b] Core services include family consultation, counseling, legal consultation, respite assistance, psychoeducational groups, and support groups but exclude intake, assessment/reassessment and wait lists.

TABLE 2
CAREGIVER RESOURCE CENTERS
CLIENT STATUS SUMMARY
07/01/2006 through 06/30/2007

	Total	Bay Area CRC	Redwood	Los Angeles	Inland	Del Oro	Southern	Coast	Mountain	Valley	Del Mar	Orange
Total Clients at Start of Report Period	9,704	1,562	1,228	1,612	471	1,004	1,077	368	479	965	229	709
# New Clients Added	3,830	498	407	603	241	336	503	162	256	501	116	207
# Cases Re-opened [a]	42	0	9	4	0	2	11	1	3	6	0	6
Total Active Clients During Report Period [b]	13,576	2,060	1,644	2,219	712	1,342	1,591	531	738	1,472	345	922
# Cases Closed	3,514	52	690	530	157	309	509	201	193	458	124	291
Total Open Cases at End of Report Period [c]	10,136	2,008	963	1,695	567	1,046	1,096	333	545	1,017	221	645

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

b This total only Includes clients who have been assessed and are on the CRC respite wait list. Caregivers who have only been through the intake process, but have not been assessed, are not included.

c Subtracts 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]
07/01/2006 through 06/30/2007

Program Services [b]	Total Clients	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]	6,783	617	1,060	556	1,567	475	446	584	327	300	723	238	507
Served Assessment	3,726	339	555	377	599	151	308	502	161	257	497	114	205
Reassessment													
Full Reassessment	3,775	343	299	484	485	290	296	405	163	215	783	82	273
Status Change	4,249	386	722	678	526	165	316	507	201	254	462	127	291
Family Consultation	13,561	1,233	2,197	1,752	2,005	310	1,246	1,501	789	749	1,724	428	860
(Avg. number per month)	3,160	287	404	370	360	56	332	370	249	210	507	132	170
Counseling (Individual)	289	26	35	49	32	4	29	34	18	15	18	37	18
Legal/Financial Consult.	361	36	67	83	57	5	12	53	27	28	6	23	0
Psychoeducational Groups	679	68	127	94	85	26	0	42	33	22	219	4	27
Link2Care [e]	1,698	154	292	154	133	214	128	431	67	63	78	15	123

[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)
07/01/2006 through 06/30/2007

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	1,628	148	178	142	223	115	143	97	91	138	275	142	84
Respite: Adult Day Care	160	15	8	22	10	10	29	3	8	25	13	19	13
Respite: In-home	1,360	124	141	115	205	102	119	95	79	127	235	71	71
Respite: 24-hour (out of home)	32	--	6	0	0	12	1	0	1	0	6	1	5
Respite: 24-hour (in-home)	71	--	22	8	0	0	6	0	3	0	25	0	7
Respite: Camp	45	--	42	0	0	3	0	0	0	0	0	0	0
Respite: Transport	17	--	0	0	0	0	0	0	0	0	7	9	1
Respite: Other [g, h]	112	--	4	0	10	0	0	1	0	1	17	79	0
Respite (Avg. number per month)	629	57	81	53	93	38	55	47	38	55	75	48	46
Respite Wait List	5,958	542	978	423	977	510	651	531	267	397	783	100	341
Caregiver Retreat	426	53	38	14	62	68	0	0	27	43	67	0	107
Support Groups	1,107	101	59	169	87	12	58	157	110	170	168	81	36
(Avg. number per month)	325	30	17	47	25	4	15	49	37	51	43	26	11

[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 sine 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
07/01/2006 through 06/30/2007

Type of Service	Total Units	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] Provided	6,783 intakes conducted	617	1,060	556	1,567	475	446	584	327	300	723	238	507
Assessment	4,037 assess. conducted	367	556	377	599	153	616	502	161	257	497	114	205
Reassessment													
Full Reassessment	5,061	460	340	576	541	333	762	497	213	269	1,109	93	328
Status Change	4,674 reassess. conducted	425	757	685	530	171	658	507	201	271	475	128	291
Family Consultation [c]	36,955 hours	3,360	2,575	4,301	4,436	579	3,484	4,831	4,851	2,737	4,532	2,262	2,367
Counseling (Individual) [c]	1,396 hours	127	125	222	97	24	330	103	97	65	67	183	83

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)
07/01/2006 through 06/30/2007

Type of Service	Total Units	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	384 hours	38	49	82	82	6	15	53	39	28	6	24	0
Psychoeducational Groups [d] Provided	7,100 hours	710	1,114	1,477	1,170	287	0	546	497	117	1,549	57	286
Total Respite [e]	224,819 hours	20,438	11,025	19,720	57,626	21,996	15,798	10,217	13,630	14,589	19,620	19,157	21,441
Respite: Adult Day Care [f]	4,616 days	420	59	652	556	140	635	44	287	804	224	696	519
Respite: In-home	164,699 hours	14,973	7,508	12,804	53,550	15,994	8,761	9,826	10,301	8,953	14,262	10,140	12,600
Respite: 24-hour [g] (out of home)	24 hr days	--	38	0	0	206	2	0	17	0	14	5	132
Respite: 24-hour (in home)	564 24 hr days	--	144	98	0	0	106	0	38	0	93	0	85
Respite: Camp [d] 414	90 24 hr days	--	84	0	0	6	0	0	0	0	0	0	0
Respite: Transportation	1,235 1-way trip	--	0	0	0	0	0	0	0	0	159	944	132
Respite: Other [f]	5,558 hours	--	36	0	184	0	0	83	0	8	1,222	4,025	0
Avg. # Months on Respite Wait List	N/A	24	40	23	16	52	25	11	24	16	18	16	20
Caregiver Retreat [d]	1,822 24 hr days	--	76	187	126	140	0	0	54	759	150	0	330
Support Groups [d]	9,839 hours	894	411	1,448	649	54	1,077	1,554	1,035	1,337	1,054	1,006	214

[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)[a]
07/01/2006 through 06/30/2007

CRC Service Type	Average Hours	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 Consultation	2.7	1.2	2.5	2.2	1.9	2.8	3.2	6.1	3.7	2.6	5.3	2.8
Counseling (Individual)	4.8	3.6	4.5	3.0	6.0	11.3	3.0	5.4	4.3	3.7	4.9	4.6
Legal/Financial Consult	1.1	0.7	1.0	1.4	1.2	1.3	1.0	1.4	1.0	1.0	1.0	0.0
Psychoeducational Groups	10.5	8.8	15.7	13.8	11.0	0.0	13.0	15.1	5.3	7.1	14.3	10.6
Respite Care[b]	138.1	61.9	138.9	258.4	191.3	110.5	105.3	149.8	105.7	71.3	134.9	255.3
Support Groups	8.9	7.0	8.6	7.5	4.5	18.6	9.9	9.4	7.9	6.3	12.4	5.9

[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 11.5 hours per month or 2.9 hours per week.

TABLE 6
CAREGIVER RESOURCE CENTERS
DEPRESSION AND HEALTH INDICES (FROM ASSESSMENT TOOLS)
07/01/2006 through 12/31/2006

CRC	Adapted Zarit[a] 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?
	Median score	Median score	Yes %	Excellent	Good	Fair	Poor	Yes %
Bay Area	19	16	60%	10.3%	55.4%	26.2%	8.2%	33.0%
Redwood	19	15	58%	25.1%	50.3%	18.9%	5.7%	23.3%
Los Angeles	18	15	64%	12.9%	51.4%	27.9%	7.8%	24.6%
Inland	21	16	51%	10.3%	57.5%	26.4%	5.7%	34.5%
Del Oro	16	11	65%	15.2%	61.6%	18.1%	5.1%	17.5%
Southern	17	14	55%	17.9%	55.5%	21.8%	4.8%	27.4%
Coast	19	13	67%	20.3%	53.2%	22.8%	3.8%	26.9%
Mountain	21	10	69%	13.4%	58.9%	21.4%	6.3%	20.8%
Valley	12	13	68%	12.7%	48.5%	27.4%	11.4%	32.1%
Del Mar	19	13	64%	14.0%	49.1%	24.6%	12.3%	32.8%
Orange	21	15	47%	18.3%	45.0%	26.6%	10.1%	33.0%
All CRCs[b]	18	14	61%	15.2%	53.1%	24.2%	7.4%	27.6%

[a] Subjects who score more than 17 on the Adapted Zarit Interview are considered to have "high burden." Subjects who score more than 16 on the CES-D index have clinically significant symptoms of depression

[b] This row shows the score when all clients are taken as a group. It is not an average of the other rows.

TABLE 7
CAREGIVER RESOURCE CENTERS
AMOUNT OF RESPITE CARE PROVIDED
07/01/2006 through 06/30/2007

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	1,628	178	142	223	115	143	97	91	138	275	142	84
Average Monthly Respite Caseload [a]	629	81	53	93	38	55	47	38	55	75	48	46
Total Hours of Respite [b]	221,579	7,785	19,720	57,626	21,996	15,798	10,217	13,630	14,589	19,620	19,157	21,441
Average Number of Hours of Respite per Family Client	352	96	372	620	579	287	217	359	265	262	399	466
Average Number of Hours of Respite per Family Client per Month [c]	29	8	31	52	48	24	18	30	22	22	33	39
Average Number of Hours of Respite per Family Client per Week [d]	7	2	7	12	11	6	4	7	5	5	8	9

a Figure represents the total monthly caseload at all 11 CRCs statewide; the average monthly caseload across CRCs is 57 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
DMH CONTRACT AMOUNT BY CRC [a]
7/1/2006 THROUGH 6/30/2007

CONTRACT	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
	$10,872,227	$1,125,307	$883,962	$1,873,679	$873,097	$881,235	$887,266	$874,303	$860,715	$870,954	$860,806	$880,903

a. Source: California Department of Mental Health, November 2007.

TABLE 9
CAREGIVER RESOURCE CENTERS
EDUCATION AND TRAINING ACTIVITIES
07/01/2006 through 06/30/2007

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	11,617	2,286	325	1,116	8	102	4,403	238	206	2,400	382	151
OTHER EDUCATION/TRAINING EVENTS												
2. Total number of persons attending	2,503	0	399	65	60	0	1,329	456	39	72	83	0
ORIENTATION TO CRC SERVICES												
3. Total number of persons attending	7,754	455	633	506	0	0	934	0	0	4,220	1,006	0
Total	21,874	2,741	1,357	1,687	68	102	6,666	694	245	6,692	1,471	151

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

TABLE 10
CAREGIVER RESOURCE CENTERS
TOP TEN UNMET NEEDS/SERVICE GAPS IDENTIFIED
BY CRCS IN THEIR SERVICE REGIONS
07/01/2006 through 06/30/2007

NEEDS IDENTIFIED	**# OF CRCS REPORTING**
Adult Day Care	7
Transportation	6
Respite	5
TBI Services and Resources	5
Services in Rural Areas	5
Home Care (affordable)	3
SNF/Residential Care (affordable)	2
Bilingual Services	2
Case Management Services	2
Support Groups	2

TABLE 11
CAREGIVER RESOURCE CENTERS
MAJOR NEEDS/INFORMATION REQUESTED BY FAMILIES/CAREGIVERS AT CRC INTAKE [a]
07/01/2006 through 06/30/2007

NEEDS IDENTIFIED	# REPORTING	% REPORTING [b]	RANK
General Information/Orientation to Brain Impairments	4,463	65.8%	1
Emotional Support	3,451	50.9%	2
Respite Care (for the caregiver)[c]	3,226	47.6%	3
Direct Care of the Adult With Brain Impairment [d]	1,967	29.0%	4
Other	1,724	25.4%	5
Behavior Management Advice	1,367	20.2%	6
Financial Advice/Aid	1,124	16.6%	7
Legal Information/Advice	899	13.3%	8
Placement Help	467	6.9%	9
Diagnostic/Medical Advice	298	4.4%	10
Rehabilitation	58	0.9%	11
Public Policy/Research	7	0.1%	12

[a] Needs identified are based on responses from 6,783 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 12
CAREGIVER RESOURCE CENTERS
MAJOR NEEDS/INFORMATION REQUESTED BY PROVIDERS/GENERAL PUBLIC AT CRC INTAKE [a]
07/01/2006 through 06/30/2007

NEEDS IDENTIFIED [e]	# REPORTING	% REPORTING [b]	RANK
General Information/Orientation to Brain Impairments	137	23.4%	1
Other	17	2.9%	2
Direct Care of the Adult with Brain Impairment [d]	15	2.6%	3
Respite Care (for the caregiver) [c]	14	2.4%	4
Emotional Support	13	2.2%	5
Placement Help	8	1.4%	6
Legal Information/Advice	4	0.7%	7
Training	4	0.7%	8
Financial Advice/Aid	4	0.7%	9
Diagnostic/Medical Advice	1	0.2%	10
Public Policy/Research	1	0.2%	11
Rehabilitation	1	0.2%	12

a Needs identified are based on responses from 586 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.
e Due to temporary data compatibility issues, these figures do not include provider data from Bay Area CRC.

TABLE 13
CAREGIVER RESOURCE CENTERS
COMPARISON OF CRC RESPITE VOUCHER COSTS AND SKILLED NURSING FACILITY (SNF) COSTS
07/01/2006 THROUGH 06/30/2007

Service	**Average Cost per Client per Month**	**Average Cost per Client per Year**
CRC Respite (Voucher)	$144	$1,726 [a]
Skilled Nursing Facility: Medi-Cal	$3,797 [b]	$45,569
Skilled Nursing Facility: Private Pay	$5,031 [c]	$60,372

[a] Based on total expenditures and family client caseload figures for CRC respite voucher services for FY 2006-2007.

[b] Source: California Department of Health Services, Medi-Cal Policy Division, Rate Development Branch, Long-Term Care Reimbursement Unit.

[c] Source: This 2006 estimate was reported by California Advocates for Nursing Home Reform (CANHR website: http://www.canhr.org/medcal/Medi_Cal_Overview200608.pdf).

CALIFORNIA'S CAREGIVER RESOURCE CENTERS
SITE DISTRIBUTION LIST

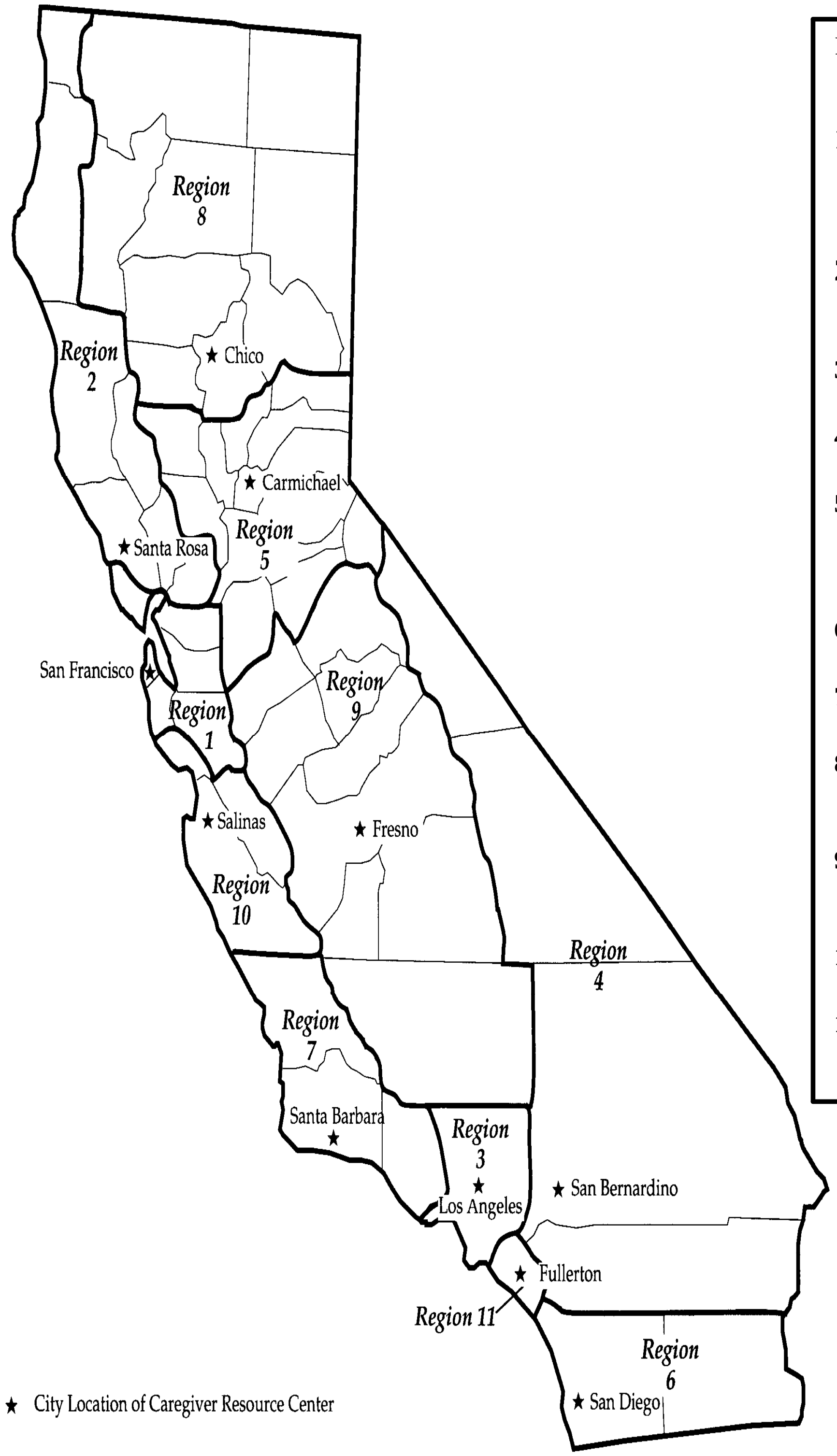
Site Number, CRC, and Counties Served	*Host Agency*	**Program Information**
(01) BAY AREA CRC Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara	Family Caregiver Alliance Kathleen Kelly Executive Director 180 Montgomery St., Suite 1100 San Francisco, CA 94104 (415) 434-3388 (800) 445-8106 E-Mail: kkelly@caregiver.org	Donna Schempp, LCSW Director, Programs and Services 180 Montgomery St., Suite 1100 San Francisco, CA 94104 (415) 434-3388 (800) 445-8106 (statewide) FAX: (415) 434-3508 E-Mail: info@caregiver.org Web: www.caregiver.org
(02) REDWOOD CRC Del Norte, Humboldt, Lake, Mendocino, Napa, Solano, Sonoma	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	Nancy Powers-Stone, LCSW 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
(03) LOS ANGELES CRC Los Angeles	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	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

Site Number, CRC, and Counties Served	**Host Agency**	**Program Information**
(04) INLAND CRC Inyo, Mono, Riverside, San Bernardino	Inland Caregiver Resource Center Robert Jabs, Ph.D. President, Board of Directors 1420 E. Cooley Dr. Suite 100 Colton, CA 92324 (909) 514-1404	David Fraser, MSW 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 Nevins, MBA 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: mnevins@deloro.org Web: www.deloro.org
(06) SOUTHERN CRC San Diego, Imperial	Southern Caregiver Resource Center, Inc. Craig Homer President, Board of Directors 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432	Lorie Van Tilburg, LCSW 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.scrc.signonsandiego.com
(07) COAST CRC San Luis Obispo, Santa Barbara, Ventura	Rehabilitation Institute at Santa Barbara Cottage Hospital 320 W. Pueblo St., Santa Barbara, CA 93105	Mary Sheridan, MFT Director Coast Caregiver Resource Center 1528 Chapala St., Suite 302 Santa Barbara, CA 93101 (805) 962-3600 (800) 443-1236 (regional) FAX: (805) 967-5060 Email: sheridan@coastcrc.org Web: www.coastcrc.org

Site Number, CRC, and Counties Served	**Host Agency**	**Program Information**
(08) MOUNTAIN CRC Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity	CSU Chico Research Foundation Jeanne Thomas, Ph.D. Chair, Center Policy Board California State University, Chico Chico, CA 95929-0450 (530) 898-6171	Susanne Rossi, MSW 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, Tuolumme	Valley Caregiver Resource Center Chris Morse President, Board of Directors 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154	Margery Minney, MSW 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	John Beleutz, MPH Executive 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 Steve Lustgarden
(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, LCSW 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	Leah Eskenazi, MSW 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: leskenazi@caregiver.org Web: www.caregiver.org
CALIFORNIA DEPARTMENT OF MENTAL HEALTH	Gartia Bansah, MSW TBI/CRC Program Administrator 1600 9th Street, RM 130 Sacramento, CA 95814 (916) 654-3529 FAX (916) 653-0200 E-Mail: gartia.bansah@dmh.ca.gov Web: www.dmh.cahwnet.gov	

MAP OF CALIFORNIA'S CAREGIVER RESOURCE CENTERS



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[xl]	1,418,681[xli]
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 fr 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.