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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 <sup>d</sup> Provided	7,100 hours	710	1,114	1,477	1,170	287	0	546	497	117	1,549	57	286
Total Respite <sup>e</sup>	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 <sup>f</sup>	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 <sup>g</sup> (out of home)	24 hr days	--	38	0	0	206	2	0	17	0	14	5	132
Respite: 24-hour (in home)	24 hr days	--	144	98	0	0	106	0	38	0	93	0	85
Respite: Camp <sup>d</sup> 414	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 <sup>f</sup>	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 <sup>d</sup>	1,822 24 hr days	--	76	187	126	140	0	0	54	759	150	0	330
Support Groups <sup>d</sup>	9,839 hours	894	411	1,448	649	54	1,077	1,554	1,035	1,337	1,054	1,006	214

<sup>d</sup> Total hours reflect the sum of hours received by each participant at a group event

<sup>e</sup> All respite figures have been converted to hours to obtain total respite hours.

<sup>f</sup> Assumes an average of seven hours per day.

<sup>g</sup> Includes overnight and weekend respite care at hospitals and residential facilities.

TABLE 5  
 CAREGIVER RESOURCE CENTERS  
 AMOUNT OF CRC SERVICE PER CLIENT (in hours)<sup>a</sup>  
 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 <sup>b</sup>	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 <sup>a</sup> 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 <sup>b</sup>	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 <sup>a</sup>	629	81	53	93	38	55	47	38	55	75	48	46
Total Hours of Respite <sup>b</sup>	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 <sup>c</sup>	29	8	31	52	48	24	18	30	22	22	33	39
Average Number of Hours of Respite per Family Client per Week <sup>d</sup>	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

b Overall monthly caseload 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 <sup>a</sup>  
 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 <sup>a</sup>	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

<b>NEEDS IDENTIFIED</b>	<b># OF CRCS REPORTING</b>
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 <sup>a</sup>  
 07/01/2006 through 06/30/2007

NEEDS IDENTIFIED	# REPORTING	% REPORTING <sup>b</sup>	RANK
General Information/Orientation to Brain Impairments	4,463	65.8%	1
Emotional Support	3,451	50.9%	2
Respite Care (for the caregiver) <sup>c</sup>	3,226	47.6%	3
Direct Care of the Adult With Brain Impairment <sup>d</sup>	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 <sup>a</sup>  
 07/01/2006 through 06/30/2007

<b>NEEDS IDENTIFIED <sup>e</sup></b>	<b># REPORTING</b>	<b>% REPORTING <sup>b</sup></b>	<b>RANK</b>
General Information/Orientation to Brain Impairments	137	23.4%	1
Other	17	2.9%	2
Direct Care of the Adult with Brain Impairment <sup>d</sup>	15	2.6%	3
Respite Care (for the caregiver) <sup>c</sup>	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

<i>Service</i>	<b>Average Cost per Client per Month</b>	<b>Average Cost per Client per Year</b>
CRC Respite (Voucher)	\$144	\$1,726 <sup>a</sup>
Skilled Nursing Facility: Medi-Cal	\$3,797 <sup>b</sup>	\$45,569
Skilled Nursing Facility: Private Pay	\$5,031 <sup>c</sup>	\$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](http://www.canhr.org/medcal/Medi_Cal_Overview200608.pdf)).

# CALIFORNIA'S CAREGIVER RESOURCE CENTERS

## SITE DISTRIBUTION LIST

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

<b><i>Site Number, CRC, and Counties Served</i></b>	<b>Host Agency</b>	<b>Program Information</b>
<b>(04) INLAND CRC</b>  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: <a href="mailto:dfraser@inlandcaregivers.org">dfraser@inlandcaregivers.org</a>
<b>(05) DEL ORO CRC</b>  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: <a href="mailto:mnevins@deloro.org">mnevins@deloro.org</a> Web: <a href="http://www.deloro.org">www.deloro.org</a>
<b>(06) SOUTHERN CRC</b>  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: <a href="mailto:lvantilburg@caregivercenter.org">lvantilburg@caregivercenter.org</a> Web: <a href="http://www.scrs.signonsandiego.com">www.scrs.signonsandiego.com</a>
<b>(07) COAST CRC</b>  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: <a href="mailto:sheridan@coastcrc.org">sheridan@coastcrc.org</a> Web: <a href="http://www.coastcrc.org">www.coastcrc.org</a>

<i>Site Number, CRC, and Counties Served</i>	<i>Host Agency</i>	<i>Program Information</i>
<b>(08) MOUNTAIN CRC</b>  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: <a href="mailto:smrossi@csuchico.edu">smrossi@csuchico.edu</a> Web: <a href="http://www.caregiverresources.org">www.caregiverresources.org</a>
<b>(09) VALLEY CRC</b>  Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, Tuolumne	Valley Caregiver Resource Center Chris Morse President, Board of Directors 3845 North Clark, Suite 201 Fresno, CA 93726 (559) 224-9154	Margery Minney, 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: <a href="mailto:mminney@valleycrc.org">mminney@valleycrc.org</a> Web: <a href="http://www.valleycrc.org">www.valleycrc.org</a>
<b>(10) DEL MAR CRC</b>  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: <a href="mailto:steve@hpcn.org">steve@hpcn.org</a> Web: <a href="http://www.hpcn.org">www.hpcn.org</a> * replaced Steve Lustgarden
<b>(11) ORANGE CRC</b>  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: <a href="mailto:cellano@stjoe.org">cellano@stjoe.org</a> Web: <a href="http://www.caregiveroc.org">www.caregiveroc.org</a>

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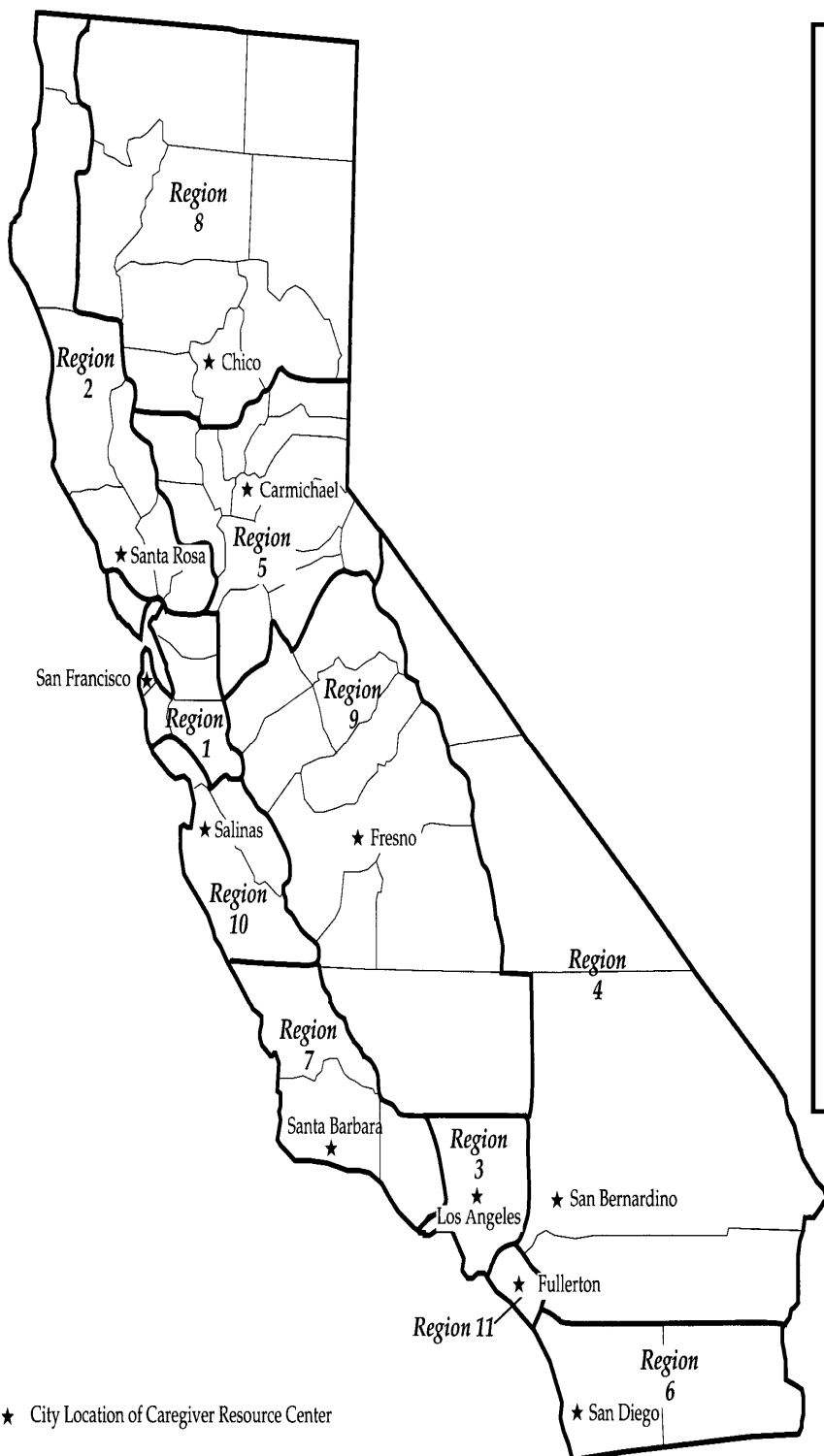
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MAP OF CALIFORNIA'S CAREGIVER RESOURCE CENTERS



★ City Location of Caregiver Resource Center

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



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

Many of the diseases and disorders that affect the brain are progressive and their incidence and prevalence increase with age. Caring for those with adult on-set cognitive impairments frequently becomes a 24-hour, 7-days a week role. As the population ages, the need for care and for understanding the impact of these disorders on families is becoming even more pressing. A report released by the Federal Interagency Forum on Aging-Related Statistics,<sup>i</sup> 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.<sup>ii</sup> 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.<sup>iii</sup>

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<sup>iv</sup>**

<b>DIAGNOSIS/CAUSE</b>	<b>PEOPLE DIAGNOSED ANNUALLY</b>
Alzheimer's Disease	360,000 <sup>v</sup>
Amyotrophic Lateral Sclerosis	5,000 <sup>vi</sup>
Brain Tumor	36,400 <sup>vii</sup>
Epilepsy	134,000 <sup>viii</sup>
HIV (AIDS) Dementia	1,196 <sup>ix</sup>
Huntington's Disease	N/A
Multiple Sclerosis	10,400 <sup>x</sup>
Parkinson's Disease	50,000 <sup>xi</sup>
Stroke	750,000 <sup>xii</sup>
Traumatic Brain Injury	85,000 <sup>xiii</sup>
<b>TOTAL ESTIMATED INCIDENCE</b>	<b>1,431,996</b>

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**

<b>DIAGNOSIS/CAUSE</b>	<b>People Currently Living with the Disorder: Low Estimate</b>	<b>People Currently Living with the Disorder: High Estimate</b>
Alzheimer's Disease	2,320,000 <sup>xiv</sup>	4,000,000 <sup>xv</sup>
Amyotrophic Lateral Sclerosis	20,000 <sup>xvi</sup>	30,000 <sup>xvii</sup>
Brain Tumor	350,000 <sup>xviii</sup>	350,000 <sup>xix</sup>
Epilepsy	1,984,000 <sup>xx</sup>	2,000,000 <sup>xxi</sup>
HIV Encephalopathy (dementia)	14,537 <sup>xxii</sup>	58,150 <sup>xxiii</sup>
Huntington's Disease	30,000 <sup>xxiv</sup>	30,000 <sup>xxv</sup>
Multiple Sclerosis	250,000 <sup>xxvi</sup>	350,000 <sup>xxvii</sup>
Parkinson's Disease	500,000 <sup>xxviii</sup>	1,500,000 <sup>xxix</sup>
Stroke	4,000,000 <sup>xxx</sup>	4,600,000 <sup>xxxi</sup>
Traumatic Brain Injury	2,500,000 <sup>xxxii</sup>	5,300,000 <sup>xxxiii</sup>
<b>TOTAL PREVALENCE</b>	<b>11,986,537</b>	<b>18,218,150</b>

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**

	<b>United States</b>	<b>California</b>
Total Population	284,796,887 <sup>xxxiv</sup>	34,501,130 <sup>xxxv</sup>
Total Population 18+	211,604,087 <sup>xxxvi</sup>	25,082,322 <sup>xxxvii</sup>
Total Households	105,480,101 <sup>xxxviii</sup>	11,502,870 <sup>xxxix</sup>
Total Estimated Adults with Brain Impairment		
a. Low Estimate	11,968,537 <sup>xl</sup>	1,418,681 <sup>xli</sup>
b. High Estimate	18,218,150 <sup>xlii</sup>	2,159,474 <sup>xliii</sup>
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 <sup>xliv</sup>		
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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- <sup>i</sup> 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/>
- <sup>ii</sup> 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](http://www.aging.state.ca.us/html/stats/map_narrative.htm)
- <sup>iii</sup> 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](http://www.aging.state.ca.us/html/stats/oldest_old_narrative.htm)
- <sup>iv</sup> 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.
- <sup>v</sup> 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.
- <sup>vi</sup> 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](http://www.ninds.nih.gov/health_and_medical/pubs/als.htm)
- <sup>vii</sup> 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.)
- <sup>viii</sup> 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.)
- <sup>ix</sup> Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(No. 2): 18.
- <sup>x</sup> 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](http://www.ninds.nih.gov/health_and_medical/pubs/multiple_sclerosis.htm).
- <sup>xi</sup> American Parkinson's Disease Association. (n.d.). *What the patient should know*. Retrieved October 22, 2002 from <http://www.parkinson.org/pdedu.htm>
- <sup>xii</sup> National Stroke Association. (n.d.). *Stroke facts*. Retrieved October 22, 2002 from [http://www.stroke.org/pages/press\\_disease.cfm](http://www.stroke.org/pages/press_disease.cfm)
- <sup>xiii</sup> 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.)
- <sup>xiv</sup> 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.
- <sup>xv</sup> 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>
- <sup>xvi</sup> 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](http://www.ninds.nih.gov/health_and_medical/pubs/als.htm)
- <sup>xvii</sup> 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>
- <sup>xviii</sup> 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.)
- <sup>xix</sup> Ibid.
- <sup>xx</sup> 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.)
- <sup>xxi</sup> National Institute of Neurological Disorders and Stroke. (2000). *Seizures and epilepsy: Hope through research*. Retrieved October 22, 2002 from [http://www.ninds.nih.gov/health\\_and\\_medical/pubs/seizures\\_and\\_epilepsy\\_htr.htm](http://www.ninds.nih.gov/health_and_medical/pubs/seizures_and_epilepsy_htr.htm)
- <sup>xxii</sup> 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.)
- <sup>xxiii</sup> 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.)
- <sup>xxiv</sup> 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](http://www.ninds.nih.gov/health_and_medical/pubs/huntington_disease_htr.htm)
- <sup>xxv</sup> Ibid.
- <sup>xxvi</sup> 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](http://www.ninds.nih.gov/health_and_medical/pubs/multiple_sclerosis.htm)
- <sup>xxvii</sup> Ibid.
- <sup>xxviii</sup> 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](http://www.ninds.nih.gov/health_and_medical/pubs/parkinson_disease_htr.htm)

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