

CALIFORNIA'S CAREGIVER RESOURCE CENTER SYSTEM  
THE COMPREHENSIVE ACT FOR FAMILIES AND CAREGIVERS OF  
BRAIN-IMPAIRED ADULTS



CALIFORNIA DEPARTMENT OF  
Mental Health

A Report to the Legislature in Response to  
Assembly Bill (AB) 14 (Bronzan), Chapter 1374, Statutes of 1992

Produced for  
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January 1, 2002

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## EXECUTIVE SUMMARY

This report addresses the progress of the *Comprehensive Act for Families and Caregivers of Brain-Impaired Adults*<sup>1</sup> between July 1, 2000 and June 30, 2001. This time period marks the sixteenth year of implementation of this statute demonstrating California's commitment to serving family caregivers. The report profiles family caregivers and the adults with brain impairment they care for and includes: 1) the cost and amount of each service provided; 2) an assessment of the nature and extent of the demand for services which provide respite; 3) an analysis of the program in deterring the institutionalization of adults with brain impairment; and 4) recommendations for ensuring that unmet needs of brain-impaired persons and their families are identified and addressed with appropriate programs and services.

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

Governor Gray Davis signed the FY 2000-01 State Budget with a \$3 million augmentation to the CRC system to expand and increase services to families and caregivers of adults with brain impairments. As reflected in this report, the most significant increase in client services as a result of this augmentation was in the area of respite care.

During Fiscal Year (FY) 2000-01:

- The substantial \$3 million budget augmentation given to the CRC System for FY 2000-01, 93% of which was distributed to the eleven Caregiver Resource Centers, facilitated increases in the total number of individuals receiving at least one CRC service, (from 12,348 to 14,201) and the number of families receiving CRC respite assistance (from 1,701 to 2,206),<sup>2</sup> representing 15% and 30% increases respectively over FY 1999-2000 figures in these areas.
- **The average service use per client across all CRC core services (includes those receiving respite and/or other services) was 40.4 hours, a 24% increase over the average service use of 32.6 hours per client during FY 1999-2000.** Most family caregivers received an average of 5.5 hours of caregiver support services<sup>3</sup> beyond basic information and comprehensive assessment, excluding respite assistance.

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

<sup>2</sup> FY 2000-01 data are current as of October 2001.

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

- A total of 6,274 family caregivers completed the intake process, contacting a CRC for the first time. *Seventy percent* of those completing intake went on to receive additional CRC services.
- The annual expenditure for respite care voucher services at the 11 CRCs was \$3,360,577 or an average of \$3,244 per family caregiver per year. The average monthly cost per family caregiver was \$288, of which \$270 was provided by the CRCs. The average monthly cost for a Medi-Cal patient (\$3,381 in 2000) in a California skilled nursing facility is nearly *12 times* the average monthly cost of CRC respite services. The average monthly private pay nursing home cost is about *14 times* (\$4,163 in 2000) the average monthly cost of CRC respite services.
- **The average time clients must wait for CRC respite assistance is 17 months. At the end of FY 2000-01, 3,722 family caregivers were on respite waiting lists at CRCs in California.**

Key findings from the CRC statewide assessment database are as follows<sup>4</sup>:

- The typical caregiver is 60 years old. *Fifty percent* of caregivers are 60 years of age or older; one in five (20%) are at least 75 years old or older.
- The family caregiver is most likely to be a female (75%), typically a wife or an adult daughter.
- Caregivers provide an average of 12.3 hours of care per day – more than a full-time job.
- Caregivers receive only an average of 11.4 hours of help per week from family or friends. Close to 7 out of 10 (68%) caregivers feel they receive ‘far less’ and ‘somewhat less’ help from family or friends than they need.
- One-third (33%) of caregivers reported feeling “depressed,” while 57% were scored as “depressed” using the Center for Epidemiological Studies Depression Scale (CES-D). Overall, 44% report high burden levels, and 40% of the caregivers say their physical health is now worse than five years ago.

The need for **basic information continued to be the number one need expressed by caregivers at intake** followed by emotional support and respite care. For caregivers who went on to receive the more in-depth CRC assessment, these same key needs were reported. While there are some difficult cases where it may not be possible for family caregivers to keep their loved ones at home, information and support services help to deter the institutionalization of the care recipient.

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<sup>4</sup> Data are from the CRC Uniform Assessment Database 2000. See METHODOLOGY for more detailed information.

The following recommendations address the needs of California's caregivers of brain-impaired adults:

1. Increase the number of caregivers receiving core CRC services through information and education campaigns organized at the local level.
2. Advance the ability of more family caregivers to maintain loved ones with brain impairment at home by using National Family Caregiver Support Program funds for family consultations, counseling, and respite services.
3. Promote the need for appropriate and affordable long-term care options for care recipients and their family caregivers through public awareness at local and state levels.
4. Increase assistance to underserved caregiver populations, particularly minority and rural caregivers, through the development of affordable, accessible, and culturally appropriate long-term care services.
5. Advance the use of technology in reaching isolated caregivers, e.g., the web-based Link2Care Project, e-mail communications, Internet information.
6. Form collaborations with the private sector to provide caregiving resources to caregivers working outside the home.
7. Coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers.
8. Support research to: 1) prevent, diagnose, treat, and cure/rehabilitate brain-impairing conditions; 2) measure and analyze the impact of brain disorders on family and caregiver well-being, and the impact of service interventions.

## ISSUE

Dramatic technological, medical, social, and environmental changes over the last several decades have resulted in extended longevity for persons with adult-onset brain diseases/impairment. A secondary effect of this demographic trend has been the need for wide-ranging, organized services to meet the physical and emotional needs of these individuals (care recipients)<sup>5</sup> and their primary caregivers. The cognitive, behavioral, and psychological changes associated with brain impairment in individuals with Alzheimer's disease, stroke, Parkinson's disease, Huntington's disease, and traumatic brain injury often result in difficulties with activities of daily living (bathing, eating, dressing), memory functions, and emotional and mental well-being. In turn, these difficulties promote physical and emotional burn-out, financial stress, and self-sacrifice among family caregivers, exacting enormous tolls on families, communities, and society. To cope, caregivers require a broad array of information over an extended period of time.

To address the needs of caregivers of brain-impaired adults, Chapter 1658, Statutes of 1984, was enacted, which created statewide support services for the growing population of family caregivers caring for individuals receiving limited assistance from existing services. The caregiver became the new client – representing the family member or other informal caregiver struggling to care for a loved one who did not fit into traditional mental health or aging systems. This legislation provided critical support for adults with Alzheimer's, Parkinson's, stroke and other brain diseases and disorders. Despite different diagnoses within the definition of adult-onset brain impairment, family caregivers shared common concerns and challenges: isolation, emotional distress, lack of information and community resources, and drastic changes in family roles.

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

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

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<sup>5</sup> Throughout the remainder of this report the term "care recipient" is used to refer to the adult with brain impairment.



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

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

This report addresses these requirements and provides information on the eleven CRCs for the period July 1, 2000 through June 30, 2001.

## **BACKGROUND**

### *History*

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

Through grass-roots efforts, a San Francisco task force was convened in 1976 to investigate the chronic care problems of middle-income Americans with irreversible brain impairment. Two years later, DMH awarded a special grant to the task force, then known as the Family Survival Project, to conduct a needs assessment of the San Francisco community to determine the number of adults with brain impairments and available services.

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

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

### ***Phasing-In of CRC Sites***

Implementation began in FY 1984-85 with continuation of Family Caregiver Alliance as the first CRC serving the greater San Francisco Bay Area. DMH also awarded the contract for the SRC to the Family Caregiver Alliance in 1985. All eleven regional CRC sites were operational by 1989. **In FY 2000-2001, the total contract award to the eleven resource center sites and the SRC was \$12,247,000, representing a \$3 million dollar augmentation over the previous fiscal year.**<sup>6</sup> See Appendix A, Site Distribution List, for a listing of site names, host agencies, and counties covered.

### ***Overview***

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

## **OBJECTIVES**

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

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

Additionally, CRCs are mandated to:

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<sup>6</sup> Includes \$200,000 for training and services for Huntington's disease families mandated under Chapter 551, Statutes of 1995.

- Provide centralized access to information about, and referrals to, local, state, and federal programs;
- Coordinate with other organizations serving adults with brain impairment, their families and caregivers;
- Assist in the identification and documentation of service needs;
- Promote the development of necessary community programs regionally; and
- Cooperate with the SRC and the DMH in the implementation of this program.

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

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

## METHODOLOGY

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

1. ***CRC Services Automation System*** and ***Caller/Caregiver Provider Tracking System (CCPTS)*** include data collection reporting requirements on all clients served, date of service, service mix, and case status. Major data components used in this report include:
  - a. **All individuals completing the CRC intake process** (e.g., the total number of callers, caller ethnicity and a summary of the callers' identified needs);
  - b. **The number of family caregivers served** and average service mix during the fiscal year;
  - c. **The units of service** (i.e., amount of service) **for each service** provided to family caregivers during the fiscal year;
  - d. **Expenditures for voucher services** as reported in the CRC Services Automation System; and
  - e. **Co-payments for respite services** paid by family caregivers.
2. ***Quarterly Progress Reports*** include CRC progress on staffing and administrative functions; the documentation of any new unmet needs identified regionally; and activities and accomplishments in five strategic plan objectives.
3. ***Family caregiver assessment data*** are obtained using a uniform, comprehensive assessment instrument to determine the well-being of family caregivers who contact the CRCs for help beyond basic information. Reassessment, conducted at six-month intervals, examines changes in the caregiver's situation, the impact of services, and on-going service needs.

## FINDINGS

This section of the report provides findings from all three key sources of information to present a detailed and accurate description of caregivers served by the CRCs, the persons they care for, and the services provided to these individuals through the CRCs. First, a descriptive profile of care recipients and caregivers is presented. Second, findings, as specified in the legislation, addressing the cost and amount of services provided, the demand for respite care, the effectiveness of the program in delaying or deterring institutionalization, and the identification of unmet needs and service gaps for care recipients and their family caregivers in California are reported (Tables and Figures used for this report are presented on pages 23-48). Last, an outline of the CRC System Strategic Plan Goals and achievements are presented with recommendations to meet caregiver needs for the FY 2001-2002.

### *Profile of Care Recipients and Family Caregivers*<sup>7</sup>

#### **A. Selected Care Recipient Characteristics:**

All family caregivers served by CRCs are caring for adults with brain impairment (the care recipient). These individuals are typically older, ranging in age from 18 to 102 years old, with an average age of 75. *Eighty-three percent* of care recipients are at least 65 years of age; 64% are 75 years of age and older; and 21% are at least age 85. *Eighty-eight percent* of care recipients are age 60 and older.

Care recipients are more likely to be female (53%) than male (47%). They mainly live with their spouse only (51%), or with their spouse and/or others (34%). Proportionately few care recipients live alone (8%) or in nursing homes (2%) when the caregiver first calls the CRC for help and support.

The median household income range for the care recipient population in 2000 was between \$26,000 and \$35,999, significantly below \$46,802 – the 2000 reported median income in California<sup>8</sup>.

*Sixty-seven percent* of care recipients have a dementing illness, principally Alzheimer's disease (31%), but also Parkinson's disease (9%), Huntington's disease (3%), and other dementias/degenerative diseases (24%). *Twenty-two percent* had a stroke, 4% are traumatic brain injury survivors, and 2% have brain tumors or other non-degenerative disorders. The great majority of adults with brain impairment (83%) have a confirmed diagnosis.

*Ninety percent* of care recipients experienced the onset of disease/disorder within the range of less than one year to ten years, with an average of 4.8 years across all care recipients. *Ten percent* of the population has lived with their brain disease/disorder for 11 years or longer.

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<sup>7</sup> CRC Uniform Assessment Database 2000 (N = 3,120 family caregivers).

<sup>8</sup> Source: U.S. Bureau of the Census, Income of Household by State, Table E., rev. September 25, 2001.

*Thirty-one percent* of the care recipients have out-of-pocket health care expenses. *Forty-eight percent* are enrolled in a health maintenance organization (HMO).

### **Problem Behaviors Associated with Brain Impairment:**

These care recipients have strikingly heavy care needs. As reported by their caregivers, they average 9 memory and behavior problems, commonly related to the individual's cognitive deficits (e.g., communication, concentration), and nine functional problems related to inabilities to perform daily tasks (e.g., bathing, feeding, dressing; using the telephone, performing chores).

Slightly more than half (53%) of care recipients are unable to perform three to five activities of daily living (ADLs) and 31% cannot perform one or two ADLs. Nearly seven in ten (69%) cannot be left alone and need constant supervision, and 40% wake their caregiver at night; 46 % are incontinent.

### **B. Selected Caregiver Characteristics:**

*The typical caregiver served at California's CRCs is a 60-year old female who has been caring for her husband with Alzheimer's disease for three to five years.*

Caregivers are predominantly female (75%), and range in age from 18 to 99 years with an average age of 60. *Fifty percent* of the caregivers are 60 years of age or older. One in five (20%) is 75 years of age and older. *Twenty-four percent* are between the ages of 36-50 years.

Caregivers served by CRCs are typically spouses (47%), while 41% are adult children and 12% represent "other" relationships to the care recipient.

Family caregivers are most likely to identify themselves as the "primary" caregiver (94%) and to live with the care recipient.

The majority of family caregivers served by the CRCs are white (79%), 8% are Hispanic, 8% are African American, 4% are Asian/Pacific Islander, and 2% are reported as other ethnic groups.

**Over half (57%) the caregivers *under* the age of 65 also work outside the home, either in full-time (41%) or part-time (16%) jobs.**

### **Caregiver Well-Being:**

Depression is a serious problem for family caregivers. Nearly six in ten (57%) CRC family caregivers show clinical symptoms of depression.<sup>9</sup> Caregivers generally report high stress due to their caregiving situation, irrespective of their care recipient's specific diagnosis. Overall, 46% report burden of care that ranges from "quite a bit" to "extreme," 66% report significant health problems, and 40% of the caregivers say their physical health is now worse than five years ago.

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

### **Caregiver Social Support:**

Family caregivers served by CRCs report that they provide an average of 86 hours of care a week to their care recipient, or an average of about *12.3 hours per day*. By comparison, these caregivers receive only eleven hours per week of help from family and friends in the care of their relative. Typically, the "informal support" the caregiver receives from his/her own family and friends includes respite, housekeeping, grocery shopping, meals, personal care, and/or managing financial/legal issues.

### **Caregiver Service Needs:**

The greatest caregiver needs, reported by caregivers, at assessment, were for general information/orientation (69%), emotional support (68%), and respite care (65%). *Twenty-eight percent* needed assistance with managing their impaired relative's behavioral problems and 24% needed legal assistance.

### ***Evaluation Components***

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

#### **1. The costs and amount of each service provided.**

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

The top four CRC services<sup>10</sup> used by family caregivers (in rank order) include: **1) family consultation; 2) follow-up information and referral; 3) in-home respite assistance; and 4) support group** (Figure 1).

The majority of family caregivers (53%) used one service only (beyond intake and assessment) during the fiscal year. The proportion of family caregivers utilizing two services, 31%, remained the same as last fiscal year, and family clients using three or more services increased to 16% from 14% in FY 1999-00 (Figure 2). **The most common service mix was family consultation for long-term care planning with either follow-up information and referral or CRC respite assistance.**

During FY 2000-01, **a total of 14,201 family caregivers utilized one or more services** at the eleven CRC sites in California (Table 1), a 15% increase over the previous year (FY 1999-00). Of these, 10,476 **(74%) received core CRC services** (i.e., services beyond just information or assessment). The average service use per client across all CRC core services was 40.4 hours during the fiscal year. However, caregivers using CRC respite substantially skewed this average. When respite users are removed, family caregivers received an average of 5.5 hours of service

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<sup>10</sup> Excludes those caregivers completing only an intake and/or an assessment or reassessment.

per year (Table 1), up from 3.5 hours in FY 1999-00. Of those receiving core services, a smaller number of family caregivers become part of the active, ongoing caseload of caregivers served by CRCs. **A total of 9,178 family caregivers had active cases<sup>11</sup>** during at least some portion of FY 2000-01 (Table 5), a 17% increase over the previous year (FY 1999-00).

Tables 2 and 3 show the total number of family caregivers receiving CRC services by service type, and the total amount of service used, respectively. Table 4 shows the average amount of service used per family caregiver, by service during FY 2000-01. Table 6 and Figure 3 show voucher service expenditures.

**A total of 6,274 family caregivers<sup>12</sup> completed the intake process** across the eleven CRC sites, a 2% decrease over the past year. For family caregivers completing intake, **72% continued on to receive follow-up information and referral.** Caregivers received an average of 1.1 hours of follow-up information during the fiscal year.

As shown in Table 5b, a total of **3,420 caregivers completed a CRC in-home assessment** to determine their needs for further services, measure their stress and burden, and to develop a care plan. Slightly more than half (55%) of caregivers completing intake went on to be assessed. The number of in-home assessments conducted during FY 2000-01 increased by 3% over the number of assessments conducted during FY 1999-00.

A total of 4,097 **family caregivers received a reassessment<sup>13</sup>** conducted at six-month intervals to examine change in caregiver well-being over time. Total reassessments increased by 23% over the previous fiscal year.

**A total of 8,433 family caregivers received an average of 2.2 hours of family consultation service each during the fiscal year.** Family consultations offer some combination of information and advice, planning and problem-solving consultation, and/or emotional support and intervention with existing service systems.

A total of 393 family caregivers<sup>14</sup> each received an average of about 7.2 hours of **family-focused education and training.** These typically small group events provide practical information to better enable families to understand brain disorders, manage daily care, cope with stress, and plan for long-term care.

A total of 938 caregivers received an average of 8.5 hours of emotional support and information exchange through attendance at CRC-sponsored support groups. A total of 240 caregivers

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<sup>11</sup> The active caseload total excludes caregivers who receive only intake and/or follow-up information and referral. Caregivers with active cases receive an initial assessment and continue to receive routine reassessments, in addition to other CRC services.

<sup>12</sup> Another 1,562 service providers and members of the general public also completed a CRC intake during FY 2000-2001.

<sup>13</sup> Another 3,873 caregivers received a “status change” in cases where the adult with brain impairment or caregiver had died or the caregiver had moved out of the CRC region.

<sup>14</sup> An additional 10,992 professionals and individuals from the general public also attended. (Table 10).



attended **psychoeducational groups**, offered by seven CRCs. Caregivers received an average of 14 hours of this service (or about 1.8 hours for a typical eight-week group session). These structured sequential class series combine training on practical coping skills, self-care and relaxation techniques.

A total of 331 caregivers received an average of four hours of **individual counseling** to offer more in-depth emotional support and mental health intervention beyond family consultation. For caregivers who received counseling from subcontracted therapists (e.g., by voucher) the average cost per client was about \$240 for four one-hour sessions (about \$60 per session).

A total of 505 caregivers received an average of 1.1 hours of **legal/financial consultation** with a CRC contract attorney as part of the long-term care planning process. The average CRC cost per family client for this service was \$111 (Table 6). Regional variations in legal consultation costs at CRCs are shown in Figure 4.

A total of 2,206 family caregivers received CRC **respite assistance**,<sup>15</sup> receiving an average of about 351.4 hours of respite during the year (Tables 2 and 4). The proportion of family caregivers receiving respite services increased 30% this fiscal year, compared to fiscal year 1999-00, due in part to the state augmentation of the CRC System budget (Figure 5). Respite services, while delivered to the care recipient, are designed primarily to benefit the family caregiver by relieving the caregiver's constant care responsibilities. Utilization of respite varied from site to site based on caregiver need and the availability of funds and services. (Figures 6 and 7).

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

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

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

Caregivers, who completed the uniform assessment process, reported the need for emotional help as slightly greater than the need for respite care (68% and 65%, respectively). This level of need is related to the strain these families experience:

- *Twenty-nine percent* of caregivers feel moderately burdened, 30% feel burdened quite a bit, and 16% feel extremely burdened; 16% percent indicate that they felt 'a little' burdened.

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<sup>15</sup> Note that some families use more than one type of respite. Therefore, the sum of the total percentages for individual types of respite exceed 100 percent.

- *Twenty-seven percent* of caregivers rate their overall health as fair to poor, and 40% say their physical health is now worse than five years ago.
- **Caregiver depression is high: 57% of caregivers exhibit symptoms of clinical depression.**

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

By the end of FY 2000-01, the eleven CRCs provided a total of 364,069 hours of respite care to 2,206 families (Tables 8, Figure 5), as noted earlier the increased number of clients receiving respite care can be directly attributed to the \$3 million budget augmentation the CRC System received in FY 2000-01. About 1,036 families, on average, received respite services each month at the eleven CRCs (or 94 families per site per month).

- On average, caregivers received seven hours of respite care per week (Table 8).
- **The average caregiver received about six months of CRC respite care during the fiscal year. This accounts for the provision of all forms of respite, including short-term and emergency respite to some families; it also reflects attrition – those who end respite services when the care recipient dies or must be placed in a residential facility.**
- Among caregivers using in-home respite, 56% used the vendor in-home respite option; fewer (44%) used “direct pay” in-home respite.
- Because of the lower cost of "direct pay" in-home respite, **caregivers utilizing the direct-pay option received approximately twice as much service**—(174 hrs. vs. 81 hrs.) on average, per family caregiver (Figure 8).
- The annual expenditure for respite care voucher services at the eleven CRCs was \$3,360,577 or an average of \$3,244 per family caregiver per year (Table 9).
- The total expenditures for CRC respite care services *including family caregiver share of cost* was \$3,706,762 or \$3,460 per family caregiver per year (Table 9).
- On average, nearly **three quarters (73%) of families who received respite services contributed toward this care through co-payments**, based on family income and household size. (Table 9).
- Annual co-payment income collected from families amounted to \$346,185 or 9 percent of the total cost, thereby reducing the total costs to the State (Table 9).
- **The average monthly cost of CRC respite voucher services per family caregiver was \$288**; \$270 was provided by the CRCs. Family caregivers contributed, on average, an

\$18 co-payment (Table 9).

The average cost per family caregiver per month varied from region to region, based on budget allocations for respite, availability of community respite options, and amount of respite care provided per family. Most CRCs provided respite services for \$200 to \$350 per client per month to maximize the number of family clients served.

As of June 30, 2001, a total of 3,722 California family caregivers remained on CRC respite lists (Table 2). Since demand for respite services continues to exceed the resources available at CRCs, **family caregivers in need of respite care waited an average of 17 months on a respite waiting list before receiving CRC respite assistance** (Table 3).

Throughout the fiscal year, a total of 3,873 cases were closed. Of cases closed providing a reason, one-third were closed due to the care recipient's death (33%); in 5% of the cases, the caregiver died or moved. A total of 581 family caregivers reported placing their relative in a residential facility (primarily in a skilled nursing facility) during FY 2000-01 (Table 5, Figures 9 and 10). Since caregivers are on CRC respite waiting lists for an average of 17 months, invariably some caregivers experience the death or institutionalization of care recipients prior to receiving respite services.

It is important to note that respite services alone may not meet the multi-faceted needs of family caregivers. At the time of assessment, nearly seven in ten (68%) families indicated a need for emotional support. CRCs work to integrate mental health interventions and ongoing contact with family caregivers to ensure a complementary package of supportive services. For the caregivers on respite waiting lists, these other CRC services can help bolster families and help them cope with the burden of care.

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

Maintaining a loved one at home with a brain impairment/disorder can be extremely difficult especially when the brain-impaired adult experiences increased confusion, which often leads to paranoia and difficult behaviors. Take the example of Ms. J:

*Ms. J is an 83-year-old Caucasian female who lives with and cares for her 79-year-old brother, Mr. J, in a rental home they have shared since he was diagnosed with Alzheimer's Disease in 1998. When a CRC Family Consultant initially met with Mr. J, she noted he was very confused, anxious and suspicious. At that first visit, Mr. J indicated that he believed his sister was his mother and simultaneously expressed deep resentment toward Ms. J for being in "his" home." He believed she was there only to take his money. In fact, they shared all expenses.*

*Over the last year, changes in her brother's condition had led Ms. J to evaluate her role as caregiver. While she wanted to continue to provide her brother's care at home, she was under extreme stress worrying that her brother would do something to change their living situation without her knowledge. Her anxiety and tension related to this concern were further exacerbated by her health condition – chronic back pain, a condition, which in turn, her doctor*

*felt was exacerbated by her caregiving demands. At the time of the consultation, Ms. J said she was exhausting herself trying to please her brother and since he could not retain information, her attempts to mitigate his fears and anxieties by way of "explaining" were not working.*

*To immediately address this family emergency, the Family Consultant and Ms. J. agreed the primary goal for Ms. J in her family consultations would be learning effective communication and behavior management skills. After three sessions, Ms. J was calmer, more relaxed, and able to recognize that unless she met her own physical and emotional needs, she could not successfully meet her brother's needs. Once she felt confident that her needs were valid and she had the skills to meet them with no risk to her own security, she arranged for regular in-home respite care. Ms. J's health has since improved significantly, and she says she feels much less anxious in general.*

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

As was shown with Ms. J, families must be informed about all their options and they must be given support in a time of crisis. Without help, caregivers may reach the point where they become depressed or ill leaving two people in need instead of one. And, particularly if the caregiver is elderly, one or both may end up in a nursing home. These situations can be tragic in both personal and financial terms.

CRC data show that most caregivers contacting CRCs are middle age or older and have modest incomes. Consequently, caregivers are likely to have long-term care needs but limited ability to pay for them. Without affordable community-based care, many families needing long-term care will resort to Medi-Cal to pay the costs.

**The average monthly cost for a Medi-Cal patient in a California skilled nursing facility was \$3,381 in 2000 —nearly 12 times the \$288 average monthly cost of CRC respite services. Private pay nursing homes cost residents about 14 times (\$4163 per month) the cost of CRC respite (See Table 7 for medi-cal and private pay rate references).**

As previously noted, during FY 2000-01, CRCs spent \$3,360,577 providing respite assistance to a total of 2,206 California caregivers. **If each of these family caregivers were forced to place their relative in Medi-Cal nursing homes, the cost would be staggering – nearly \$ 91million per year.**<sup>16</sup> Clearly, even if CRC respite services help only some portion of family caregivers to deter the institutionalization of the care recipient, the State realizes enormous savings.

While it may not be appropriate in some very difficult cases for family to continue providing care at home, CRC services help many families who are deciding what is best for their family

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<sup>16</sup> Based on \$41,136 annualized 2000 SNF Medi-Cal rate x 2,206 persons.

member and themselves. For these families, information and support services help deter the institutionalization of a loved one. It must be noted however, that among the 3,722 families on CRC respite waiting lists, some care recipients will be placed in a nursing home before CRC respite services became available. Unfortunately it is unknown how many of these families might have avoided or postponed that painful decision had subsidized respite care been an option.

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

In order to better understand the magnitude of needs experienced by adults with brain impairment and their families, it is important to first estimate the scope of the problem. An estimated 1.2 million people aged 18 years and older are diagnosed annually with adult onset brain disease/disorders (Appendix C, Table 1). Between 13.3 and 16.1 million individuals age 18 and over are afflicted with the more common brain disorders and diseases diagnosed (i.e., the number of people currently living with impairment – Appendix C, Table 2). Even more striking, as many as 13 to 16 percent of the United States and California households may be dealing with the burden of caring for a loved one with an adult onset brain disease/disorder (Appendix C, Table 3).

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

- 1) **Seven out of ten (70%) family caregivers and 55 % of service providers/general public requested basic information** about adult-onset brain disorders, a full range of caregiving issues, and the scope of CRC services. Resource information is critical at the time of diagnosis and remains important throughout the duration of the caregiving commitment. Information is needed and requested in the areas of home care and behavior management, emotional support, financial/legal considerations, placement help, and long-term care planning and alternatives.
- 2) **Emotional support was a key need for well over half (61%) of families and 25 % of service providers.** This indicates a **high demand for services, such as counseling and support groups**, where caregivers can begin to unburden themselves from the enormous stresses of their situations.
- 3) **More than half (58%) of the caregivers and 19 % of service providers<sup>17</sup> indicated a need for respite care services.**

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

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<sup>17</sup> Respite needs identified by service providers indicate respite for the family caregiver.

### ***Other Identified Needs***

Table 11 depicts the top ten unmet needs/service gaps identified by CRCs throughout FY 2000-2001 in their respective regions. The most common needs included: adult day care, respite care, support groups (bilingual), transportation, residential care options, and a range of services for traumatic brain injury survivors.

To identify available resources throughout California, the Statewide Resources Consultant (SRC), in cooperation with the eleven CRCs, revised and updated two statewide resource directories in 2001: *The Directory of California Respite Resources* and *The Directory of California Support Groups for Caregivers of Adults with brain impairment* (each containing over 1,500 resource listings statewide).

### ***Addressing Identified Service Needs***

For CRCs across the state, education and training events continue to be one of the best vehicles for families and professionals to address the high demand for information about brain impairments and caregiver support options. **Statewide and regional training events** (Table 10) promote opportunities to develop working relationships with organizations and professionals and for increasing public awareness of brain diseases/disorders and caregiving. These events teach family members about care techniques and other low-cost interventions. Such training can promote greater coping skills and foster prevention of crisis situations. Additionally, the development of new training materials, such as program development in rural communities, and education for special populations, allows CRCs to address the tremendous demand for information, support and assistance for a wide range of caregiving experiences.

**The 11 CRCs provided family-focused educational seminars and workshops for 393 CRC family clients. A significant 36,446 participants attended conferences and other educational events held regionally and statewide on issues related to caregiving and adult-onset brain impairments, during FY 2000-01, a 29% increase over the previous year.**

Throughout FY 2000-01 a series of educational seminars addressing the needs of caregivers of Huntington's Disease patients were conducted throughout the state following the mandate under Chapter 551, Statutes of 1995, to develop trainings related to the care of individuals with Huntington's Disease.

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

### ***Strategic Plan Goals and Achievements***

The **three-year statewide strategic plan (1997-2000)** developed jointly by the CRC Directors, DMH, and SRC to provide a vision for the CRC system in the new millennium was extended to include this FY 2000-01. A new strategic plan has been approved to cover July 1, 2001- June

30, 2003. With the additional year, many goals and objectives were fulfilled through collaborative efforts with the DMH, the SRC, and regionally by CRCs.

Highlights of this extended year's implementation of the 1997-2000 Strategic Plan goals and accomplishments are as follows:

## **I. Improve the Quality and Effectiveness of Services**

### ***a. Increase Uniformity Across CRC Sites in Reporting***

- The Resource Specialist at FCA provided consultation to the CRCs on updating the Caregiver Resource Database (CRD) – the annual updating of all community resources was completed during the second quarter of the fiscal year.
- The SRC Data Management/Technical Assistant provided training throughout the year to CRC staff on data reporting to increase uniformity in reporting.

### ***b. Enhance Staff Training and Professional Development***

- SRC staff continued to provide hands-on technological support to the CRCs regarding the data reporting systems (Services Automation), through regional trainings, phone consultations, and several CRC site visits.
- Staff from all the CRCs attended the Statewide CRC conference, “Caregiving 2001,” in Berkeley, which provided information, workshops, and training seminars on a variety of salient caregiving issues, e.g., sexuality and dementia, drugs and dementia, mediating family conflict, etc.
- Throughout the year, CRC staff attended local meetings and professional development workshops on a wide range of issues – caregiving, brain impairment, and crisis intervention for the elderly.

## **II. Tailor CRC Information to Culturally Diverse and Changing Populations**

### ***a. Update, Improve, and Translate CRC Information***

- Throughout the year, the CRCs updated and translated CRC materials into Spanish, Vietnamese, Hmong, and Chinese languages.

### ***b. Seek Additional Resources to Target Ethnic Groups with Outreach Services***

- Several CRCs hired bilingual/bicultural staff this year to address the needs of underserved communities – Spanish-speaking, Chinese, Cambodian, East Indian, and Vietnamese.

***c. Adapt CRC Services to Meet the Needs of Working and Adult Children***

- Through evening and weekend hour support groups, consultations, and training workshops, the needs of working and adult children caregivers have been met by many of the CRCs this year.

**III. Increase Resources to Serve More Caregivers**

***a. Explore Opportunities to Increase Funding***

- The CRC System received state budget augmentations through the Department of Mental Health for FY 2000-2001 to serve more caregivers – significant increases in services to caregivers were made in the area of respite services during this fiscal year.
- CRCs have formed new partnerships and community collaborations to increase services to caregivers and meet the eligibility requirements for funding through the National Family Caregiver Support Program (NFCSP). All of the CRCs have submitted or have plans to submit grant proposals to their Area Agencies on Aging (AAAs) for the NFCSP funds. Many CRCs have pursued additional funding in their respective regions through fundraisers, sponsorships from local agencies, and county contracts.

**IV. Work Toward Inclusion of Family Caregivers in a Comprehensive, Affordable, and Coordinated Long-Term Care System**

***a. Increase Visibility of Distinct Needs of Caregivers & Adults with Cognitive Impairment at Local, State and Federal Levels***

- The CRC 2001 Statement of Preferred Public Policies was distributed to key policymakers and elected officials locally and every member of the California Legislature at their Sacramento offices, as well as to the California Congressional delegation in Washington, D.C., to educate them about priority needs and concerns for family caregivers.
- During the year, CRC staff throughout California participated in critical local planning meetings with key stakeholders to visibly advocate for the needs of family caregivers. The SRC continued to participate in the development of public policy supportive of family caregivers in California through attendance of statewide meetings and the publication of Policy Digest – an on-line public policy journal tracking the development and passage of caregiving legislation affecting family caregivers.

***b. Provide Leadership at the State and Local Levels***

- The CRCs staff continued their active engagement with the Department of Aging and local AAAs regarding the distribution of NFCSP funds. Many participated in regional Long-Term Care Council meetings and other public forums promoting the needs of



family caregivers.

## **V. Promote Research and Technology Projects that Lead to Program & Policy Innovation for Caregivers and Adults with Brain Impairment**

### ***a. Design and Pilot Test Technology Applications***

- At the end of the FY 2000-2001, all of the CRCs had either joined or expressed interest in joining the Link2Care Project – a subscriber website providing on-line information and support to caregivers developed and piloted by FCA in conjunction with the SRC. Southern CRC also implemented new web-based technology in conjunction with UCLA, and Orange CRC launched a new website.
- The first phase of a new integrated information system designed to meet the multiple needs of statistical reporting and database management for the CRC System was launched. A needs assessment at the CRC level was completed and the CRC System selected several products for review. The second phase of this project is expected to be completed during FY 2001-2002 and will focus on a pilot testing of the selected product and preparation for the changeover to the new technology.

### ***b. Identify and Develop Research Projects***

- Several CRCs collaborated with local universities and medical centers performing research on behalf of caregivers and care recipients – Southern CRC with UCLA is addressing managed care, Del Oro CRC partnered with UC Davis in recruiting participants for a ginkgo biloba study, and Orange CRC is working with CSUF on a multi-lingual needs assessment.
- The SRC began analysis of the CRC assessment data to determine the impact of caregiving on caregiver health over time. Variables studied include depression, arthritis, cancer, etc. Completion of the analysis is expected during FY 2001-2002.

## RECOMMENDATIONS

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

1. Increase the number of caregivers receiving core CRC services through information and education campaigns organized at the local level.
2. Advance the ability of more family caregivers to maintain loved ones with brain impairment at home by using National Family Caregiver Support Program funds for family consultations, counseling, and respite services.
3. Promote the need for appropriate and affordable long-term care options for care recipients and their family caregivers through public awareness at local and state levels.
4. Increase assistance to underserved caregiver populations, particularly minority and rural caregivers, through the development of affordable, accessible, and culturally appropriate long-term care services.
5. Advance the use of technology in reaching isolated caregivers, e.g., the web-based Link2Care Project, e-mail communications, Internet information.
6. Form collaborations with the private sector to provide caregiving resources to caregivers working outside the home.
7. Coordinate outcome measures with recommended interventions to refine core CRC services to family caregivers.
8. Support research to: 1) prevent, diagnose, treat, and cure/rehabilitate brain-impairing conditions; 2) measure and analyze the impact of brain disorders on family and caregiver well-being, and the impact of service interventions.