A 20-YEAR PARTNERSHIP IN CARING

Sponsored by the California Department of Mental Health
A 20-YEAR PARTNERSHIP IN CARING

Prepared by the Statewide Resources Consultant
at Family Caregiver Alliance
for the California Department of Mental Health
Two decades ago in California, the words “Alzheimer’s” and “caregiver” received important recognition when landmark legislation established a network of Caregiver Resource Centers (CRC) in our state.

These nonprofit support organizations focus specifically on the needs of families and friends caring for loved ones suffering from Alzheimer’s disease, stroke, Parkinson’s disease, traumatic brain injury and other debilitating conditions. These illnesses affect memory and cognition, abilities and personality, and they carry with them the need for long-term care and assistance.

None of us is exempt from the effects of long-term illnesses. I know—Alzheimer’s has struck my family, as it has so many others. The important role families play in long-term care often goes unrecognized, and that’s why the CRC system exists—to acknowledge the difficulties they face and provide resources to help them confront their challenging job.

Under the direction of the California Department of Mental Health, 11 Caregiver Resource Centers now offer services in every region of our state. Through these centers, Californians have access to information, education, counseling and respite care. The centers offer workshops, support groups, legal advice and, perhaps most importantly, a shoulder to lean on when things get tough.

California remains at the forefront of family caregiving, and our CRC system serves as a model for other states and the nation. I proudly join in celebrating the 20th Anniversary of California’s groundbreaking system of Caregiver Resource Centers. Together, we salute the hundreds of thousands of California families who provide care for loved ones, and we honor the organizations that help them.

Best wishes,

Maria Shriver

OFFICE OF THE FIRST LADY
STATE CAPITOL • SACRAMENTO, CALIFORNIA 95814 • (916) 445-7097
WWW.FIRSTLADY.CA.GOV
I am pleased to present this report in conjunction with the 20th anniversary of California’s ground-breaking Caregiver Resource Center (CRC) system. In 1984, the California Legislature passed the Comprehensive Act for Family Caregivers of Brain-Impaired Adults (Welfare & Institutions Code Section 4362 et. seq.), thus establishing the Statewide California Caregiver Resource Centers under the direction of the state Department of Mental Health. In the two decades since, 11 CRCs have been established throughout the state to help the many families who, with love and dedication, choose to provide care for their loved ones at home as an alternative to institutionalization.

The groundwork for the CRC system was laid in San Francisco in 1977, when volunteers from the Mental Health Association joined with caregivers whose lives had been forever altered by their loved ones’ illnesses. The group realized that the urgency of the challenges they faced would grow exponentially as our population ages. Sustaining needed services would require not only determination and perseverance on the part of the volunteers, but also legislative action to change and direct public policy.

Fortunately, these goals were swiftly accomplished. California has had the unique good fortune to be blessed with visionary volunteers, skilled staff and forward-looking legislators; together they launched a grassroots movement of successful innovation and results, and together they developed a program that now serves as a model of excellence for the rest of the nation. Today, our nonprofit CRCs offer information, education, counseling and respite care as their core services, and a system of reliable and uniform assessment ensures that all resources are allocated in the most efficient way. They never forgot the importance of tracking program results and those results are a powerful testament to the value of the program.

More than 250,000 families have benefited from the wide range of services offered by our CRCs. Always, our foremost goal has been the development of programs that respond to the physical, emotional and financial stresses of long-term caregiving. The last 20 years have been a time for definition, creation, and refinement. Now, as we look ahead to the next 20 years and the aging of the Baby Boomers, we eagerly anticipate the continued success and expansion of the CRCs’ programs as they strive to seek new, innovative, cost-effective ways to assist the families who are the backbone of our long-term care system.

Congratulations on 20 years of excellence. Your dedication and tireless advocacy have led you to this success, and we look forward to your continued leadership in the future.

Sincerely,

STEPHEN W. MAYBERG, Ph.D.
Director
“Always bear in mind that our focus is on empowering family members to help themselves, rather than managing their problems for them.”

Family member & Family Caregiver Alliance
Co-Founder Suzanne Harris
This year marks the 20th Anniversary of California’s pioneering system of statewide Caregiver Resource Centers (CRCs). This important milestone—which truly represents the coming of age of a national movement—offers an opportunity to celebrate the many accomplishments of the CRCs, to recognize the changing societal and cultural landscape, and to look to the future for California caregivers.

Over the past two decades, the 11 CRCs have supplied information, education, respite and emotional support to more than a quarter million California families and friends who provide long-term care at home for loved ones suffering from chronic, debilitating health conditions. It is these dedicated families—not institutions—who provide most of the long-term care in the United States, often at great physical, emotional and financial sacrifice.

"It was all so sudden, so devastating, so overwhelming that I needed help from every direction. The Caregiver Resource Center was a lifesaver for me!"
Caregiving is rewarding, but also stressful and demanding: caregivers are faced with their loved ones’ memory loss, behavioral and personality changes, round-the-clock care needs and high care costs. Caregiving impacts both the physical and mental health of the caregiver and can result in emotional distress and economic hardship for families. More than half of the family caregivers who have been assessed at one of the California CRCs report symptoms of clinical depression. Forty percent say that daily caregiving activities negatively impact their own physical health as well. And as the population ages, the number of family caregivers will grow exponentially.

The world has fundamentally changed for this growing population of family caregivers, not only in California, but across the country. In 2005, a comprehensive range of services addresses the needs of family caregivers—needs that 20 years ago were thought too private for a public response. With the development of model support programs and services, and with the recognition of caregivers as a distinct population in need of support, there is hope and help for families. And the California Caregiver Resource Centers remain in the forefront of this profound change.

History

Started as a grassroots effort in 1976, California’s state-wide system of Caregiver Resource Centers is the culmination of one community’s determination to respond to a major health care and social need. A small group of families who were caring for loved ones with debilitating brain-impairing illnesses formed a task force and held a town hall meeting in a church basement in San Francisco.

At that time, there was no local, state or national entity that addressed the needs of families and caregivers of adults with cognitive disorders such as Alzheimer’s disease, stroke, Parkinson’s disease or traumatic brain injury. Many of the diseases that affect the brain are progressive

Helen’s Story

When we become parents and dream of what our children will grow up to become, we dare not think our worst fears. Helen, who first cared for her husband through his decline with Huntington’s disease, was traumatized to learn that two of her three adult children also carried the gene and as the disease progressed at different rates she struggled to care for them at home, with the assistance of her healthy son. She says there were days when she was so overwhelmed she had trouble getting out of bed. She wanted to remain there in the fetal position and not face the day.

With CRC assistance, Helen found a Huntington’s disease support group where she met others like herself. She began to use the community resources available to her, including assistance with transportation to medical appointments, respite care, counseling and psycho-educational classes. She reported that this package of services was the only thing that made her burden more bearable.
and their incidence and prevalence increase with age. The loss of cognitive and functional abilities affects the individual and his or her family in profound ways, yet medical and service providers were only beginning to recognize the need for programs to help sustain caregivers of those suffering from these chronic conditions.

The small task force, determined to fill the gap in services for family caregivers, was fortunate to have the support of then-Assemblyman Art Agnos. He introduced legislation to establish a demonstration pilot project, at that time called Family Survival Project, to provide family support services for caregivers of brain-impaired adults. Beginning in 1979, services that included emotional support, care planning assistance, respite care, education and legal consultation were provided to caregivers in the San Francisco Bay Area.

The task force’s early efforts had three lasting results:

- The formation of the model program in the San Francisco Bay Area;
- The genesis of a first-in-the-nation statewide network of Caregiver Resource Centers; and
- The beginnings of a movement to recognize the immense contribution of family caregivers to the long-term health care of the ill and elderly in our country.

Assemblyman Agnos then authored legislation to replicate the pilot project in other regions, ensuring that all families in California had access to these much-needed services. Signed by Governor George Deukmejian on September 30, 1984, the *Comprehensive Act for Family Caregivers of Brain-Impaired Adults* (Welfare & Institutions Code Section 4362 et. seq) established the statewide California Caregiver Resource Center (CRC) system under the California Department of Mental Health. The Caregiver Resource Centers were legislatively mandated to assist families who provide care for loved ones.

---

**Dan’s Story**

There is enormous grief in caregiving for a loved one with degenerative brain impairment as the changes in behavior and personality occur incrementally. Dan was still in love with Rose, his wife of 45 years. He was grateful to her for her sunny disposition and the caring devotion she showed him and their sons these many years. When Rose was diagnosed with Alzheimer’s disease, Dan committed to caring for her at home as long as possible. He didn’t know that he would mourn the small losses every day and that he would seldom have a moment’s peace. He called the CRC and was invited to bring Rose to participate in a weekend respite camp. It was the first break Dan had had, but it was not his last. The experience was so rejuvenating that Dan began to plan respite breaks regularly. He reported that taking better care of himself significantly elevated his ability to care for his wife.
with Alzheimer’s disease, stroke, Parkinson’s disease, traumatic brain injury, Huntington’s disease, multiple sclerosis and other cognitive disorders that occur after age 18. By 1989, ten new CRCs had been developed and all regions across the state were being served.

California was the first in the nation to develop a state-wide system to address a significant new client: the family caregiver. Previously, recognition of caregiver stress and burden, and acknowledgement of family needs along with patient needs, had fallen through the cracks.

Two additional pieces of legislation were enacted in 1984 that helped ease the plight of California caregivers. The Alzheimer’s Day Care Resource Centers (ADCRCs) were established under the California Department of Aging. The ADCRCs are specialized day care centers for individuals with dementia-related disorders. The centers also offer resources and support to families. Today there are 64 sites across California.

Under the Department of Health Services, ten Alzheimer’s Disease Research Centers of California (ARCCs) were established to provide a comprehensive assessment for individuals with memory loss; conduct research to differentiate diagnoses, causes and treatment; and assist families in understanding care needs. The CRCs work in close collaboration with the ADCRCs and the ARCCs to reach families, provide information and services to caregivers, and to educate health care professionals about memory loss disorders and related caregiver issues.

Today California’s Caregiver Resource Center system continues to provide a wide range of consumer-oriented, needs-based services, honored as best practices across the country and internationally.

Hallmarks of the California Caregiver Resource Center System

• Began as a grassroots effort with a small group of family members
• Identifies the family caregiver as the client
• Includes all adult-onset brain impairments
• Bases services and programs on expressed needs of family caregivers
• Identifies emerging trends, and incorporates nationally and internationally-recognized “Best Practices” in caregiver services
• Provides a continuum of care from first symptoms to final decisions

California was the first in the nation to develop a state-wide system to address a significant new client: the family caregiver. Previously, recognition of caregiver stress and burden, and acknowledgement of family needs along with patient needs, had fallen through the cracks.

Two additional pieces of legislation were enacted in 1984 that helped ease the plight of California caregivers. The Alzheimer’s Day Care Resource Centers (ADCRCs) were established under the California Department of Aging. The ADCRCs are specialized day care centers for individuals with dementia-related disorders. The centers also offer resources and support to families. Today there are 64 sites across California.

Under the Department of Health Services, ten Alzheimer’s Disease Research Centers of California (ARCCs) were established to provide a comprehensive assessment for individuals with memory loss; conduct research to differentiate diagnoses, causes and treatment; and assist families in understanding care needs. The CRCs work in close collaboration with the ADCRCs and the ARCCs to reach families, provide information and services to caregivers, and to educate health care professionals about memory loss disorders and related caregiver issues.

Today California’s Caregiver Resource Center system continues to provide a wide range of consumer-oriented, needs-based services, honored as best practices across the country and internationally.
The Role of the CRC System

With the oversight of the California Department of Mental Health, the CRCs:

- Provide a single point of entry for families to access a comprehensive range of services, education and support, tailored to the individual needs and diverse demographics of family caregivers.

- Educate the public and policy makers about cognitive disorders that occur in adulthood and the consequent needs of family caregivers.

- Demonstrate a replicable model of care to help families keep their loved ones at home and out of institutional care as long as feasible.

- Collaborate with other community organizations to maximize the support available to family caregivers.

Core Services include:

- **Intake:** CRCs provide a single source for information and resource referrals. A trained professional provides emotional support and answers questions on cognitive disorders, care options and available community resources.

- **Uniform Assessment:** CRCs collect information about the multiple factors that impact the needs of the family caregiver to determine the degree of caregiver stress and burden, including the caregiver’s physical and emotional health, social supports, and specific caregiving challenges.

- **Family Consultation:** CRCs offer assistance in understanding the care receiver’s diagnosis; developing an individualized care plan with linkage to needed services; problem-solving; improving communication; planning self-care for the caregiver; and preparing for the future.

"Loving, caring, giving people from the Caregiver Resource Center helped me to get back on track and opened the doors for me that I didn’t realize were there. My life has changed for the better and I owe that to a large degree to the CRC. I can’t thank you enough for all the help that has been given. Thank you!!!"

CRC Guiding Principles

The Family Caregiver Is the Client: The family caregiver needs assistance and support, through a comprehensive range of services responsive to the needs of families to enable them to keep their loved ones at home and out of institutionalized care for as long as possible.

Family Caregivers Are the Care Managers for Their Impaired Loved Ones: Families participate in planning and service delivery issues and retain maximum control over care planning and decision-making.

Broad Focus Across All Adult-Onset Brain Impairments: Families face similar needs and caregiving issues across diagnostic categories. In 2000, the National Family Caregiver Support Program further expanded the ability of some CRCs to include caregivers of older adults with any disability.
Legal Information and Advice: Consultations are available with an attorney experienced in the complex issues relevant to caring for an adult with a cognitive impairment. Information includes establishing durable powers of attorney, conservatorships, eligibility for government assistance, and financial planning for long-term-care.

Family and Professional Education: CRCs provide specialized workshops concentrating on behavior management, legal planning, diagnosis, research and treatment, stress reduction and other caregiving issues.

Counseling: Six to eight individual and/or family sessions with counselors offer emotional support and problem solving assistance to caregivers to reduce depression and stresses related to the caregiving role.

Respite Assistance: Respite provides a period of short-term relief from the constant burden of caregiving. CRCs help families locate and arrange for appropriate care for a loved one while the caregiver takes a break. Financial assistance may be available to help with the expense of in-home care, day programs, overnight care, weekend respite, or transportation for an impaired family member.

Support Groups: Regularly scheduled in-person or online gatherings of family caregivers and/or individuals with a cognitive impairment. Discussions may include an educational component as well as emotional support.

Innovative CRC Programs

Web-based Caregiver Support: The CRCs have embraced the technology available to support the service delivery system, to reach wider audiences and to provide quality information and services over the Internet.
- **Online Groups and Classes**: CRCs have pioneered online support groups and classes for caregivers to find emotional support and skill-building strategies.

- **Family Meetings**: A trained facilitator leads family meetings to assist in understanding a diagnosis, addressing the needs of the caregiver and care receiver, developing tools for family members to improve communication, mediate differences and coordinate a shared care plan.

- **Psycho-educational Groups**: CRCs are the premier providers of effective psycho-educational interventions. These classes for caregivers provide short-term practical interventions, with peer support and self-care exercises. The classes show outcomes of reduced feelings of frustration and increased caregiver competence.

### California CRCs Are the Major Providers for Psycho-Educational and Skill-Building Interventions for Caregivers

- **It Takes Two: Understanding Dementia Behavior**: Series of classes piloted by the Bay Area CRC.

- **Controlling Frustration**: A series of classes designed with cognitive and behavioral interventions and peer support.

- **To Place or Not to Place**: Piloted by the Inland CRC, offers caregivers help with the difficult decision to consider placement for their family member in a community care facility.

- **Transitions**: Piloted by Southern CRC, this series of classes is for caregivers who have recently placed a loved one in a long-term care facility.

- **Caregiver Skill Series**: Piloted by the Bay Area CRC, helps family caregivers develop in-home care expertise.

- **Powerful Tools**: Tools to reduce stress assist in making difficult caregiving decisions and prevent caregiver burnout.

- **Difficult Conversations about Difficult Decisions**: This workshop focuses on end-of-life concerns—how to begin talking; getting family together; choices about end of life.

(continued on next page)
The Role of the Statewide Resources Consultant

The Comprehensive Act for Family Caregivers also established a Statewide Resources Consultant (SRC), a role fulfilled by Family Caregiver Alliance, which also hosts the Bay Area Caregiver Resource Center. In its capacity as a centralized information and technical assistance clearinghouse, the SRC collects, analyzes and provides basic information on a variety of issues that affect adults with cognitive disorders, their families and caregivers. The SRC has developed a caregiver database, which produces caregiver profiles and service usage statistics, and the findings are published annually.

The Statewide Resources Consultant:

- Provides consultation and technical assistance to the CRCs and other public agencies;
- Develops statewide training and education packages to assist in the professional development of CRC staff;
- Manages a statewide database on family caregivers served by the CRCs and analyzes the data for trends and assessment of needs;
- Maintains the Link2Care and California CRC websites, as well as a comprehensive library on adult onset brain disorders and caregiving issues;
- Informs and updates the Department of Mental Health and the California legislature on the needs of family caregivers;
- Conducts social research on family caregiving and related issues;
- Publishes quarterly newsletters with caregiving information and advice; calendars of groups and classes; research updates; an electronic policy report; more

“I was totally blessed by the Caregiver Resource Center and my Family Consultant. It was a miracle-working program for me. I could not have survived without you!”

California CRCs Are the Major Providers for Psycho-Educational and Skill-Building Interventions for Caregivers (cont’d)

What’s Up, Doc? Communicating Effectively with Health Care Professionals: A workshop to assist family caregivers in developing effective communication techniques for dealing with the health care system.

When Everyone Talks and Nobody Listens—Working Together with Your Siblings: How to foster agreement, encourage cooperation, and provide tips for more effective communication within families.

Camps for Caring—Weekend Retreats for Individuals with Memory Loss: Two full days of structured activities in a lovely setting for the individual with memory loss.

Caregiver Retreats: Caregivers receive peer support, a break from round the clock caregiving, and a multitude of optional activities.

Early Stage Groups for Individuals with Memory Loss: Emotional support for individuals in the early stages of dementia, and separate meetings for their family caregivers.

Bilingual Outreach and Education Programs: CRCs lead the way in developing bilingual programs that reach out to a diverse audience of families and caregivers.

What’s Up, Doc? Communicating Effectively with Health Care Professionals (cont’d)
than 60 consumer focused fact sheets in multiple languages on adult-onset brain impairments and related caregiving issues; and a variety of journal articles, monographs, manuals and reports.

**California CRCs Evaluate Outcomes and Client Satisfaction and Respond to Identified Needs**

In order to determine how effective the CRC service package is, and to ensure that services continue to be designed to meet caregivers’ identified needs, an Outcomes Task Force was developed in 1999. The first goal of the task force was to identify and measure self-reported changes in caregiver behavior and feelings of competence following CRC interventions.

Recent studies show that the most effective services are those that assist family caregivers in building skills that increase feelings of competency and reduce frustration with difficult behaviors. *California’s Caregiver Resource Centers: Outcomes Report* was published by the Statewide Resources Consultant in October 2002.

Using the Uniform Caregiver Assessment data for “Caregiver Comorbidity and the Ability to Manage Stress” (Parrish, Adams, *Journal of Gerontological Social Work*, Vol. 42, 2003), the SRC studied the impact of physical health on caregivers’ well-being and ability to manage stress. It was found that difficult behaviors on the part of the care receiver and reduced social support by family and friends were significantly associated with caregiver feelings of stress and burden. The important implications for caregiver interventions were much the same as the earlier study: to continue to develop and make more widely available trainings for caregivers on managing difficult behaviors, skill-building for caregivers on managing their

**Publications by the Statewide Resources Consultant Include:**

- *Options for Supporting Informal and Family Caregiving* (1997)
- *A Study of Pre- and Post-Placement Family Caregiving for Individuals with Alzheimer’s Disease and Related Disorders* (1995)
- *A Well Deserved Break: A Description of the Range of Respite Services Offered by the California Caregiver Resource Centers* (1993)
- *Respite Care in California: Charting the Future* (1992)
own reactions to these behaviors, and to continue to work with families to increase their support systems, emphasizing the effectiveness of psycho-educational classes, counseling and support groups. The classes and groups were further developed as a result of these studies, emphasizing the commitment of the CRC system to translate research into practice.

In 2004, the SRC conducted the first statewide caregiver satisfaction survey. 1,355 family caregivers throughout the state voiced their satisfaction with services provided by one of the 11 CRCs. Ninety-seven percent of respondents indicated that they were satisfied with the overall quality of the services received from their CRC; 98 percent said they would probably or definitely recommend their CRC to others.

The Profile of Family Caregivers

Over the past 20 years the majority of individuals served by the CRCs have been women caring for a spouse or a parent with dementia. Today’s caregivers are more likely to be in the work force with children at home, and to use the Internet for information, support and resources.

In 1984, the typical family caregiver contacting a CRC was a married woman in her sixties, caring for a spouse at home. Twenty-six percent of caregivers reported working full-time. Most families (43%) had been providing care for three to six years before their first contact with a CRC.

In 2004, the typical family caregiver was a married woman in her mid-fifties (47%), more likely to be caring for a parent (38%) than a spouse (23%). Half (51%) of all caregivers receiving CRC services were also employed outside of the home. The time between the diagnosis and making the first call to a CRC now has been reduced to less than two years. (CRC Services Automation System database 2004.)

Jane’s Story

Seldom do we think about the true meaning of the phrase “for better or for worse.” That’s what Jane had promised Todd in their wedding vows, but she never anticipated the hardship of providing care for him following a serious automobile accident at age 33. The most serious injuries were to Todd’s brain. As he recovered physically, Jane began to realize that his personality had changed and that he lacked the crucial motivation to benefit from rehabilitation. She felt desperate to help him and didn’t know where to turn. When she called the CRC, she requested a consultation to help her advocate on Todd’s behalf. She was able to develop a plan of care to get the maximum benefit for his rehabilitation, and to build a financial plan for her family and a self-care plan for herself in order to preserve her marriage.
“Thank you for your services, support and friendship. You have helped me weather the challenges of caregiving for my mother who recently died. I am recommending you to a newly diagnosed family with Alzheimer’s tonight. Blessings.”

This dramatic change is attributed to a broader awareness of caregiving issues, recent medical advances in understanding brain disorders, and the successful outreach efforts of the CRCs using the Internet, the media and by building and maintaining relationships with other community organizations.

The CRCs have also been effective in reaching out to the diverse populations of California family caregivers. In 1993, the intake interview was standardized across sites to include information about caregiver ethnicity. From the baseline data collected at that time, targeted outreach

---

Joseph's Story

Joseph, a 60-year-old man, was diagnosed with Alzheimer's disease in 2003. He is married with two children. His wife, Mary, is his primary caregiver. Joseph lives with his wife and children in a suburban neighborhood. They have access to various resources, including the local pork resource center. Mary has been attending support groups and has received training in caregiving skills. She is also able to access respite care when needed.

Who's Taking Care?

Source: California’s Caregiver Resource Center System, Annual Report(s), 1984/85 through 2000/01 and supplemental unpublished data from records for FY2001 through FY2004, provided by the Statewide Resources Consultant.

Caregiver Ethnic Distribution

Source: California’s Caregiver Resource Center System, Annual Report(s), 1984/85 through 2000/01 and supplemental unpublished data from records for FY2001 through FY2004, provided by the Statewide Resources Consultant.
and education programs were developed in identified under-served communities. As a result, the percentage of nonwhite caregivers served by the CRCs had more than doubled within five years and has continued to increase steadily. By 2004, a quarter of the caregivers served by the California CRCs identified themselves as Asian, Pacific Islander, African American, Hispanic or Native American.

Two Decades of Service to California Family Caregivers

By 1989, when all eleven CRCs were fully established and the uniform caregiver assessment tool had been implemented, the SRC developed a database to track service utilization patterns of families served. Since that time, the statewide system has served more than:

- 250,000 callers with information and referral, helping them locate appropriate services and support;
- 90,000 families with personalized consultation and care assistance in planning for both present and future needs;
- 20,000 family caregivers with respite assistance, providing a brief break from care responsibilities;
- 15,000 family members with specialized support groups;
- 6,000 individuals with caregiver-focused counseling;
- 300,000 family members with education and training in caregiving skills.

“...My experience with the personnel at the CRC was a blessing. The class I took was informative, and the genuine compassionate attention was encouraging and uplifting. I believe it is imperative to keep these services available.”

Caregiver Resource Center Core Services

Source: California’s Caregiver Resource Center System, Annual Report(s), 1984/85 through 2000/01 and supplemental unpublished data from records for FY2001 through FY2004, provided by the Statewide Resources Consultant.
The Changing Landscape of Family Caregiving

Over the 20 years that the CRCs have provided services to family caregivers in California, some significant changes have helped increase public awareness about the needs of family caregivers:

- The Older Americans Act Amendment of 2000 created the National Family Caregiver Support Program (NFCSP). This new law established national recognition of the important role of family and informal caregivers of older adults and provided new federal funding for caregiving services. The CRC system was one of four programs on which the national program was modeled. NFCSP funds have come to the CRCs through the California Department of Aging, administered locally through Area Agencies on Aging. The range of health conditions has expanded to include congestive heart failure, chronic obstructive pulmonary disease, emphysema, arthritis, cancer, and other late adult-onset illnesses.

- Ronald Reagan announced to the country in November 1994 that he was diagnosed with Alzheimer’s disease. This announcement had an enormous impact on the media attention given to Alzheimer’s disease and caregiving issues.

- By the mid 1990s, Internet resources and support greatly expanded caregivers’ access to knowledge and helped reduce their isolation.

- The development of new technologies and research advances such as magnetic resonance imaging (MRI) helped lead to more accurate and earlier diagnoses of Alzheimer’s disease.

- The Baby Boomers have moved into caregiving roles for parents and spouses, creating unprecedented demand for services and programs.

Anne’s Story

The emotional impact of caregiving is overwhelming, frustrating, exhausting and saddening. On a visit home to Michigan, Anne noticed signs of confusion and disorientation in her mother, who lived alone. Anne and her husband made the difficult decision to move Mom closer so that they could oversee her care. Anne became her mother’s care manager overnight and began managing her finances and planning for in-home care. Within weeks, Anne was feeling the stress of taking care of her mother’s high level of needs and the physical and emotional toll the care was taking. Counseling provided by the CRC helped Anne let go of her guilt feelings and set limits for how much she could handle.
• Positive emission tomography (PET) imaging became a powerful new tool to detect brain plaques, one of the hallmarks of dementia, which previously could only be accomplished at autopsy.

• Treatments to slow the progress of Alzheimer’s disease began to emerge and become more widely available.

• Individuals in the first stages of dementia, now being diagnosed much earlier, began to ask for help directly. Many retain the cognitive capacity to benefit from groups and support programs. The CRCs and the Alzheimer's Association in California came together to develop programs to address the needs of those diagnosed earlier in the disease process.

• Significant advances in the treatment of stroke, including medications such as the antithrombotics, thrombolytics and neuroprotective agents, can protect the brain from secondary injury caused by stroke.

• Computer-based assistive technology made it easier for brain-impaired adults, particularly individuals with stroke and traumatic brain injury, to communicate and improve functioning.

• Guidelines for the management of traumatic brain injury, published by the Brain Trauma Foundation in 2000, provide information and education to health-care professionals who treat head injury survivors.

• Stem cell research offers enormous potential in many areas of health and medical research to develop treatments for long-term diseases such as Alzheimer’s, Parkinson’s, multiple sclerosis, stroke, diabetes and heart disease.
1977  A grassroots volunteer peer support group, with help from the Department of Mental Health, conducts a needs assessment and develops Family Survival Project as a demonstration project to provide services to family caregivers.

* Representing the “Family Survival Task Force,” Co-founder Anne Bashkiroff testifies before First Lady Rosalynn Carter about the needs of caregivers.

1979  Family Survival Project, later renamed Family Caregiver Alliance, begins a pilot project to assess caregiver needs, identify gaps in services, and develop resources to provide a range of caregiver support. Two adult day programs are established with help from the Brookdale Foundation.

1984  AB 2913 signed into law by Governor George Deukmejian establishes the California Caregiver Resource Center system (originally called Regional Resource Centers), designating the the Bay Area Regional Resource Center as the pilot project to be replicated statewide.

1985  Three new CRCs are designated and begin providing services: Inland (San Bernardino County), Redwood (Sonoma County), and Los Angeles.

1986  Second round of CRCs is designated: Coast (Santa Barbara), Del Oro (Sacramento area), and Southern (San Diego).

1987  First statewide public policy forum is sponsored by Statewide Resources Consultant to identify key issues. SRC completes one of the first studies of employed caregivers.

* Coast CRC establishes satellite offices in San Luis Obispo and Ventura

1988  Final round of CRCs is designated: Mountain, Valley, Del Mar (Monterey area), and Orange.

1989  All 11 Caregiver Resource Centers are fully operational.

* California receives “Innovations Award” from Council of State Governments recognizing the CRCs as first statewide system to comprehensively address the needs of family caregivers.

* The CRC’s Uniform Caregiver Assessment Tool is developed.

* Orange and Coast CRCs initiate Caregiver Weekend Retreat Program.

1990  SRC presents statewide teleconferences on legal planning and behavior management, beamed to 60 sites across California.

* Orange CRC publishes manual on leading Caregiver Retreats.

* Respite Weekends and Caregiver Retreats are launched by Redwood, Del Mar and Valley CRCs.

**California Caregiver Resource Center Milestones**

California was the first state in the country to pass legislation recognizing the formidable challenges of caring for a family member with a devastating condition such as Alzheimer’s disease or traumatic brain injury. I’m proud that the programs established by the Caregiver Resource Centers not only provided meaningful help for California families, but became models for the entire nation.

—Former Assemblyman and San Francisco Mayor Art Agnos
* CRCs offer training series on Alzheimer’s disease in rural areas across the state, providing access to education for family caregivers in remote areas.
* SRC publishes *Who’s Taking Care?*, profiling CRC clients.

**1991**  
* CRCs hold first Advocacy Day in Sacramento.  
* Mountain CRC establishes a Brookdale model respite day program in Plumas County.  
* Coast CRC publishes *Reaching Latino Elderly*, a handbook for human services providers.  
* Bay Area CRC receives private funding to conduct outreach to Latino, Asian and African American caregivers.  
* Mountain CRC develops the Butte County Traumatic Brain Injury Task Force.

**1992**  
* Statewide Resources Consultant sponsors the first interdepartmental statewide conference on respite policy in California with the Senate Subcommittee on Aging and the Alzheimer’s Association.  
* Bay Area CRC launches “Camps for Caring: Weekend Retreats for Adults with Memory Loss.”  
* Los Angeles CRC offers bilingual Spanish family education series.  
* Mountain CRC establishes a Brookdale model respite day program in Mt. Shasta, Siskiyou County.  
* Del Oro CRC translates CRC fact sheets to five different languages: Japanese, Vietnamese, Chinese, Hmong and Spanish.  
* Del Oro CRC collaborates with Sacramento County to launch “Respite, Recreation & Recognition” (RRR) adult day programs, later replicated at three additional sites to become independent nonprofits.

**1993**  
* Orange CRC launches Legal Workshop series on long-term care planning.  
* CRCs begin to collect baseline data on ethnicity of caregivers served and develop targeted outreach efforts to reach underserved communities.  
* Del Oro CRC establishes the Capitol Caregiver Support group, which meets monthly at the State Capitol to provide education and support for family members providing care to a loved one.  
* Los Angeles CRC takes leadership role in developing a disaster preparedness program for brain-impaired adults and frail elders, following LA quake.  
* CRC system implements “services automation system,” first statewide database on caregiver demographics and profile of service delivery.  
* An article on the California CRCs consumer-oriented approach to serving family caregivers is published in *The Journal of Case Management*.  
* The CRCs, along with the Statewide Resources Consultant, publish a monograph on statewide respite options, entitled *A Well Deserved Break*.

**1994**  
* CRCs celebrate the 10th Anniversary of the statewide system.  
* CRC Services Standard Task Force is developed to improve quality and consistency of CRC service delivery in all California communities.  
* CRCs collaborate with the Huntington’s Disease Society to develop training curricula for community agencies serving HD and Alzheimer’s populations.  
* CRCs offer a new service—short-term counseling—by adopting a statewide uniform counseling protocol to address the needs of depressed caregivers.  
* Mountain CRC establishes a Brookdale model respite day program in Yreka, Siskiyou County.  
* Director of Valley CRC is invited to the White House to advocate for long-term care.
1995

* Family Caregiver Alliance website debuts with information, resources and an online support group for caregivers.
* CRCs host four public policy forums across the state for the White House Conference on Aging.
* In collaboration with the Stanford Older Adult Center, Bay Area CRC offers psycho-educational series for caregivers on “Controlling Frustration.”
* Bay Area CRC initiates programs serving specific needs of LGBT (lesbian, gay, bisexual, transgender) community.
* Mountain CRC establishes a Brookdale model respite day program in Weaverville, Trinity County.

1996

* The National Institute on Consumer-Directed Home and Community Based Long-Term Care recognizes CRC system as a “Best Practice” model.
* CRCs increase capacity to offer psycho-educational groups across state.
* Statewide Resource Consultant publishes a consumer research report on the “Respite Choice Study” showing a strong preference for consumer-directed in-home care.
* “It Takes Two: Understanding Dementia Behavior,” a new Bay Area CRC class for managing problem behaviors, shows outcome measures of reduced caregiver frustration.
* Redwood CRC launches annual respite weekend for survivors of traumatic brain injury; participates practice skill skills by planning the activities.

1997

* In collaboration with the Alzheimer’s Association, CRCs offer support groups for individuals in the early stages of dementia and concurrent groups for their family caregivers.
* CRC Outcomes Task Force is formed to identify and implement outcome measures for services.
* Mountain CRC establishes a Brookdale model respite day program in Corning, Tehama County.

1998

* Southern CRC launches men-only caregiver support group.
* Inland CRC launches psycho-educational series, “To Place or Not to Place,” to assist families in decision-making, placement planning and evaluating long-term care facilities.
* Los Angeles CRC partners with USC Family Clinic to train residents as part of their geriatric rotation through CRC assessment, home visit and family consultation.
* Los Angeles CRC partners with SCAN, a social HMO, to develop resources for family caregivers and coordinate referrals to the CRC for follow-up.

1999

* “Guidelines for Alzheimer’s Disease Management” are released by the California workgroup, which included the SRC, Alzheimer’s Association, UCLA Alzheimer’s Disease Center, and the California Geriatric Education Center, with oversight by the Department of Health Services. The CRCs and the Alzheimer’s Association, identified as the two primary resources for caregiver education and support, collaborate in disseminating the report to physicians and medical clinics.
* Mountain CRC establishes a Brookdale model respite day program in Red Bluff, Tehama County.
* Link2Care, a secure members-only website, is launched with private funds under a collaborative effort between FCA and the University of Wisconsin, Madison, to provide caregivers with decision-making tools, consultation with experts, an information library and resource database, a caregiver journal format, and an online discussion group.
* FCA Co-founders Anne Bashkiroff and Suzanne Harris receive Rosalynn Carter Caregiving award in recognition of their leadership and innovation.
* All 11 CRCs provide regional trainings on the
“Comprehensive Curriculum for Care Providers Serving the Huntington’s Disease Affected Community.”

Valley CRC expands to three satellite offices: Modesto, Merced and California City.

2000
- The National Family Caregiver Support Program (NFCSP), using the California CRC system as one of its models, is signed into law. CRCs utilize federal funding to enhance and expand their caregiver services across the state.
- CRCs and the SRC offer a series of three statewide teleconferences on Dementia Care, Parkinson’s disease, and Huntington’s disease. The conferences are placed online for 24-hour access by families.

2001
- Los Angeles CRC launches family caregiver retreats for underserved communities; programs offered in Chinese and Spanish.
- Los Angeles CRC assists in development of “Making the Link” with local Area Agency on Aging to educate physicians about caregiver needs.
- Building on its California experience, FCA establishes National Center on Caregiving to assist other states in developing caregiver support programs.
- Coast CRC hosts systemwide class leader training, “Caring for You: Powerful Tools for Caregiving.”

2002
- Del Oro CRC receives recognition award from Sacramento County Adult and Aging Services Commission for longstanding leadership on Mental Health and Aging Conference Committee.
- Bay Area CRC conducts LGBT Community Needs Survey.
- Los Angeles CRC coordinates consortium of 25 community agencies to conduct outreach and trainings for family caregivers in Los Angeles County, entitled “EduCare.”
- FCA wins international award for Best Practices in Caregiver Support.

2003
- “Caring Counts!” statewide conference on caregiving sponsored by the California CRCs and AARP draws 400 participants to learn practical skills, find support and launch an advocacy movement for a comprehensive system of care responsive to the needs of caregivers across the state.
- “Transitions” psycho-educational group for family caregivers adjusting to their new role after placement is piloted at Southern CRC.
- “It Takes Two,” the psycho-educational model launched in 1996, is now provided in Spanish.
- Valley CRC launches employed caregiver education program on location with largest Fresno County employer.
- Redwood CRC pilots “Creative Alternative,” a psycho-educational class series utilizing art therapy for caregivers in a group setting.
- Del Mar CRC develops “Mindful Meditation” programs for caregivers.
- Mountain CRC implements the Native American Family Caregiver Support Program in collaboration with Redding Rancheria.

2004
- CRCs begin year-long celebration of their 20th Anniversary of caring for caregivers!
- In collaboration with the Statewide Resources Consultant, CRCs work to develop a new integrated client tracking system, using a web-based information network, to better analyze data on the demographic profile of caregivers served, needs identified, the impact of resources and outcomes of services provided.
- Del Oro CRC launches education and support program: “Men as Caregivers: Beyond Toughing It Out.”
Redwood CRC collaborates with the Santa Rosa Junior College Acquired Brain Injury Program to develop a conference for caregivers, planned by the students in the program.

Del Mar CRC develops Anticipatory Grief groups for family members.

Orange CRC launches educational series, “Aging with Empowerment.”

CRC system implements a uniform CRC client satisfaction questionnaire.

Looking Ahead

Caregiving, at one time a very private family concern, has become an increasingly important public issue. The California CRCs have brought these issues to the forefront by acknowledging the needs of family caregivers, educating the public about long-term health disorders and their impact on families, and by designing and delivering services tailored to the unique needs that caregivers have identified.

The American senior population, age 65 and above, is expected to double in the next 30 years from 35 million to more than 70 million. In California, where about 10 million Baby Boomers now live, the number of older adults will increase from the current 3.5 million to 7 million. In the year 2030, one of every six Californians will be over the age of 65 and more than 40 percent will be Asian, Latino or African American. Because of the state’s size and diversity, California will be challenged to be both strategic and creative to meet the needs of the aging population. In the report, Strategic Planning Framework for an Aging Population, published by the California Policy

The Experience of Caregiving

A statewide survey of CRC clients revealed:

- 74% of family caregivers are female.
- 52% of care recipients are unable to perform 3 to 5 personal activities of daily living (e.g., eating, bathing, transferring, toileting, dressing). 89% cannot perform 1 or 2 ADLs. 48% are incontinent.
- 83% of care recipients lived at home with a spouse or other relatives.
- 70% of those responding said patient could not be left alone.
- Over half (52%) of family caregivers had annual household incomes of under $36,000 (2001 dollars).
- Greatest caregiver needs were for emotional support (84%) and respite care (79%).
- Mean number of hours caregivers provided care: 81 hours per week.

Source: Caregiver Resource Centers’ 2001 Uniform Assessment Database. Population consists of 3,476 family caregivers in all regions of the state who were assessed by one of the CRCs (received services beyond basic information).
Research Center, it is estimated that today 3.2 million caregivers in California devote 3.4 billion hours to caregiving activities every year, a value of $30 billion annually. Programs offered by the CRCs help to reduce the emotional, physical, legal and financial impact on families.

Family caregivers will continue to provide the valuable care required to keep loved ones at home, and will look to the community for the sustenance that will allow them to continue to do so successfully. More and more families will need the comprehensive range of services provided by the California CRCs—innovative help designed as a tailored response to identified needs. Great progress has been made, but more needs to be done to ensure that families are able to provide the long-term care their loved ones need to remain at home and out of institutions.

The CRCs are unique: we serve family caregivers through their entire caregiving journey with a spectrum of services, education and support that responds to the evolving needs and challenges of caregivers. The CRC system will continue to build on best practices to expand and develop innovative service options, to advance the use of technology to benefit caregivers and those who may be isolated at home, and to provide education to families to increase their caregiving competence and sustain them throughout their journey.

“When we started, it was our hope that by exposing our private sorrows we might plant the seeds of a national movement for caregivers. Today, families don’t have to struggle in isolation as they care for someone with a long-term illness. For that, I am thankful.”

Family member & Family Caregiver Alliance Co-Founder Anne Bashkiroff
Caregiver Resource Centers and the Regions They Serve

Bay Area Caregiver Resource Center/ Family Caregiver Alliance
Statewide Resources Consultant
180 Montgomery Street, Suite 1100
San Francisco, California 94104
Phone: (415) 434-3389 or (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org
Alameda • Contra Costa • Marin • San Francisco
San Mateo • Santa Clara Counties

Coast Caregiver Resource Center
5350 Hollister Avenue, Suite C
Santa Barbara, California 93111
Phone: (805) 967-0220 or (800) 443-1236 (regional)
Website: www.coastcrc.org
E-mail: ccrc@silcom.com
San Luis Obispo • Santa Barbara • Ventura Counties

Del Mar Caregiver Resource Center
736 Chestnut Street, Suite F
Santa Cruz, California 95060
Phone: (831) 459-6639 or (800) 624-8304 (regional)
Website: www.hpcn.org/delmar
E-mail: hpc@hpcn.org
Monterey • San Benito • Santa Cruz Counties

Del Oro Caregiver Resource Center
5723A Marconi Avenue
Carmichael, California 95608
Phone: (916) 971-0893 or (800) 635-0220 (regional)
Website: www.deloro.org
E-mail: crc@deloro.org
Alpine • Amador • Calaveras • Colusa • El Dorado
Nevada • Placer • Sacramento • San Joaquin
Sierra • Sutter • Yolo • Yuba Counties

Inland Caregiver Resource Center
1420 East Cooley Drive, Suite 100
Colton, California 92324
Phone: (909) 514-1404 or (800) 675-6694 (California)
Website: www.inlandcaregivers.com
E-mail: info@inlandcaregivers.org
Inyo • Mono • Riverside • San Bernardino Counties

Los Angeles Caregiver Resource Center
3715 McClintock Avenue
Los Angeles, California 90089-0191
Phone: (213) 821-7777 or (800) 540-4442 (California)
Website: www.losangelescrc.org
E-mail: lacrc@usc.edu
Los Angeles County

Mountain Caregiver Resource Center
2491 Carmichael Drive, Suite 400
Chico, California 95928
Phone: (530) 898-5925 or (800) 822-0109 (regional)
Website: www.caregiverresources.org/MCRC_home
E-mail: smrossi@csuchico.edu
Butte • Glenn • Lassen • Modoc • Plumas • Shasta
Siskiyou • Tehama • Trinity Counties

Orange Caregiver Resource Center
251 East Imperial Highway, Suite 460
Fullerton, California 92835
Phone: (714) 578-8670 or (800) 543-8312 (regional)
Website: www.caregiveroc.org
E-mail: ocrc@stjoe.org
Orange County

Redwood Caregiver Resource Center
141 Stony Circle, Suite 200
Santa Rosa, California 95401
Phone: (707) 542-0282 or (800) 834-1636 (regional)
Website: www.redwoodcrc.org
E-mail: rcrc@redwoodcrc.org
Del Norte • Humboldt • Lake • Mendocino • Napa
Solano • Sonoma Counties

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, California 92123
Phone: (858) 268-4432 or (800) 827-1008 (California)
Website: www.scrc.signonsandiego.com
E-mail: scrc@caregivercenter.org
San Diego • Imperial Counties

Valley Caregiver Resource Center
3845 North Clark Street, Suite 201
Fresno, California 93726
Phone: (559) 224-9154 or (800) 541-8614 (regional)
Website: www.valleycrc.org
E-mail: info@valleycrc.org
Fresno • Kern • Kings • Madera • Mariposa • Merced
Stanislaus • Tulare • Tuolumne Counties

www.californiacrc.org