
Family Caregiver Support:
*Policies, Perceptions and Practices in 10 States Since Passage
of the National Family Caregiver Support Program*

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CALIFORNIA

OVERVIEW

California is the largest state in the nation, with about one of every eight people in the United States living within its borders.¹ The state has a sizable foreign-born population and is distinguished by its ethnic and racial makeup. Compared to the nation as a whole, California has a much greater proportion of Hispanic and Asian older persons and a smaller proportion of African American older persons.

California has a wide array of publicly funded long-term care programs administered by many state departments having different eligibility requirements, target populations and services. As a result, the state's home and community-based service system and caregiver support services are considerably fragmented, impeding policy reform and system coordination. Despite recent budget challenges, the state's efforts to expand long-term care options and support for families include the enactment of a \$500 state caregiver tax credit in 2000; moderate state general revenues directed at home and community-based care and caregiving support; and, most recently, the enactment of the first paid family leave law in the United States.

Policy attention to caregiver support services has been an explicit component of California's long-term care system since 1979, when a pilot project created the first prototype of a Caregiver Resource Center (CRC) system. A statewide CRC program was enacted in 1984 and is administered by the California Department of Mental Health (DMH); 11 CRCs now serve California's family caregivers of adults with cognitive impairment and with other chronic conditions. California's CRC system was one of the models on which the National Family Caregiver Support Program (NFCSP) was based. With the enactment of the NFCSP through the aging network and the California Department of Aging, the state's caregiver support services are now characterized by:

- ❖ Multiple caregiver support programs and services administered by various state agencies
- ❖ A unique administrative structure whereby two well-developed systems that serve large populations of older persons and their caregivers are currently managed not by the state's aging department but by its mental health and social services departments
- ❖ A large and growing state- and county-funded in-home supportive services program, also funded by Medi-Cal (California's Medicaid program), with consumer direction and direct payment to family caregivers
- ❖ Flexibility to meet the individual needs of family caregivers at the local level

California respondents noted that the major service needs of family caregivers are (1) respite, (2) family consultation, (3) support groups, (4) caregiver education and training and (5) assistance in finding formal care providers.

As California continues to expand its caregiver support programs, a key consideration will be how the state reduces fragmentation and coordinates among the state's multiple services and programs that provide support to California's family and informal caregivers.

INTRODUCTION

California represents an “old” state that provided caregiver support services prior to the passage of the NFCSP. The project team conducted in-person site visits and telephone interviews between June 12 and July 19, 2002, with government officials and key stakeholders. The team interviewed staff from the following state agencies and programs within those agencies:

California Department of Aging

- ✧ Family Caregiver Support Program (NFCSP funded)
- ✧ Aged Medicaid waiver (Multipurpose Senior Services Program)
- ✧ Alzheimer’s Day Care Resource Center (state funded)
- ✧ Alzheimer’s Day Health Care (federally and state funded)

California Department of Health Services

- ✧ Aged Medicaid waiver (Multipurpose Senior Services Program)

California Department of Mental Health

- ✧ Caregiver Resource Centers (state funded)

California Department of Social Services

- ✧ In-Home Supportive Services (federally and state funded)

California Health and Human Services Agency

- ✧ Long-Term Care Council (state funded)

Stakeholders interviewed were from:

- ✧ Alzheimer’s Association, California Council
- ✧ California Association of Adult Day Services
- ✧ California Association of Area Agencies on Aging
- ✧ California Association of Caregiver Resource Centers
- ✧ University of California at Berkeley, School of Social Welfare

Six programs are featured in this profile:

1. California NFCSP
2. Caregiver Resource Center System
3. In-Home Supportive Services
4. Aged Medicaid waiver
5. Alzheimer’s Day Care Resource Center
6. Adult Day Health Care

BACKGROUND

California is the largest state in the nation, with a population of 33.9 million residing in 58 counties.² The state is “highly urban” with metropolitan areas of more than 1 million people accounting for about three-fourths of the total population.³ California also has the highest concentration of immigrants in the nation, with foreign-born residents representing around one-quarter of the population.⁴

In 2000, personal income per capita was \$32,275, compared to the national average of \$29,676.⁵ About 16.0% of California's population live below the federal poverty level (vs. 13.3% U.S.).⁶ California ranks 10th nationally in percentage of households with Internet access.⁷ Compared to the national average, California has half the proportion of African Americans (6.7% vs. 12.3% U.S.) and a significantly greater proportion of Hispanic persons (32.4% vs. 12.5% U.S.)⁸ (table 1).

An estimated 4.7 million persons in California, or 14.0% of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). California ranks 46th nationally in its proportion of older residents (ages 60+).⁹ As with the state's population as a whole, California has a smaller proportion of African Americans ages 60+ as compared to the national average (5.3% vs. 8.4% U.S.) and a much greater proportion of Hispanic older persons (14.3% vs. 5.4% U.S.).¹⁰ Of note is California's population of Asians ages 60+, which is almost five times the national average (10.2% vs. 2.5% U.S.).

California ranks 43rd nationally in the proportion of its population ages 85 and older. In 2000, 425,657 persons, or 1.3% of California's population, were ages 85+.¹¹

An estimated 3 million family caregivers reside in California. These family caregivers provide about 2.8 billion hours of caregiving per year at an estimated value in 1997 of \$22.9 billion.¹²

Although the tax burden on California residents is about the same as the national average (\$11.34 per \$100 vs. \$11.30 U.S.),¹³ California's budget depends heavily on personal income tax and investment-related income (i.e., capital gains and stock options). The economic downturn has been especially severe in this huge state. In 2002, California experienced a \$23.6 billion deficit, stemming from a drop in personal income tax collections in 2001–02 and 2002–03.¹⁴ Forecasts suggest that the state will face substantial budget deficits for at least the next few years.¹⁵

Table 1. Selected Characteristics of CALIFORNIA and the UNITED STATES, 2000 ^a

	California	United States
Total Population Characteristics		
Total Pop. ^b	33,871,648	281,421,906
% African American ^c	6.7%	12.3%
% Hispanic ^d	32.4%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	4,742,499	45,797,200
% 60+ ^f	14.0%	16.3%
National ranking 60+ ^g	46	NA
Pop. 65+ ^h	3,595,658	34,991,753
% 65+ ⁱ	10.6%	12.4%
National ranking 65+ ^j	46	NA
Pop. 85+ ^k	425,657	4,239,587
% 85+ ^l	1.3%	1.5%
National ranking 85+ ^m	43	NA
% increase 1990–2000 60+ pop. ⁿ	12.0%	9.4%
% White (60+) ^o	67.9%	82.4%
% African American (60+)	5.3%	8.4%
% Hispanic (60+)	14.3%	5.4%
% Asian (60+)	10.2%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.2%	0.1%
% Amer. Indian/Alaska Native (60+)	0.4%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	3,009,523	25,798,370
Caregiving hours (millions) (1997)	2,801.3	24,013.1
Value of caregiving (millions) (1997)	\$22,914.3	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$32,275	\$29,676
% of pop. below poverty (1997) ^r	16.0%	13.3%
Internet		
% of households w/Internet access (2001) ^s	46.7%	41.5%
Nat'l ranking of households w/Internet access	10	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-California, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-California.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

California has a complex system of agencies and departments through which aging, health and social services are administered. The umbrella agency is the California Health and Human Services Agency (CHHSA). Of its 15 boards and departments, four oversee (either explicitly or implicitly) services that support family and informal caregivers: the California Department of Aging (CDA) and the California Department of Mental Health (DMH) explicitly; and the California Department of Social Services (DSS) and the California Department of Health Services (DHS) implicitly. California has committed sizable state general funds to programs that support family caregivers within all of these agencies except the DHS.

In 1999, CHHSA established the Long-Term Care Council^a to improve system coordination of long-term care, including the state's efforts to develop a more integrated system of home and community-based services and supports for family and informal caregivers. The council is composed of the heads of eight CHHSA departments that provide long-term care services.

The CDA serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP, among other programs. The governor appoints the director, who reports to the secretary of CHHSA.

a The council was authorized in A.B. 452 (chapter 895, statutes of 1998).

The infrastructure of California's aging network is a statewide system of 33 Area Agencies on Aging (AAAs) that serve areas ranging in area from part of one county (the city of Los Angeles) to five counties. Nineteen of the 33 AAAs are units of county government, six are private nonprofit agencies, six have "joint powers agreements,"^b one is co-located within a university and one is a unit of city government. In 1979, the AAAs incorporated the California Association of AAAs (C4A), whose mission is to, "develop a statewide system of comprehensive and integrated home and community-based services for older persons and adults with disabilities through advocacy, coordination, and education."¹⁶ Currently, 32 of the 33 AAAs are members.

California has six Medicaid waivers providing home and community-based services to different populations. The one that specifically serves the frail elderly as the Aged Medicaid waiver is known in California as the Multipurpose Senior Services Program (MSSP). It was originally approved in 1977 as a four-year demonstration and research project. The program provides case management and a range of other home and community-based services. The DHS is responsible for oversight as the "single state agency" for Medicaid. The DHS contracts with CDA to administer the program to approximately 14,600 unduplicated beneficiaries in the state (11,789 slots).

California also has the first state-funded program providing explicit family caregiver support in the country, the CRC system, administered through the DMH. The DMH, in turn, contracts with regionally based CRCs to provide an array of caregiver services. DMH also contracts with the State-wide Resources Consultant (SRC) to operate a statewide information and technical assistance clearinghouse. To aid DMH in the implementation of the CRC system, the SRC provides consultation, training, research and technical program assistance to the CRCs and other organizations in the state. The prototype for this system was first funded through a pilot project in the San Francisco Bay Area in 1979. A statewide system was phased in between 1985 and 1989. Currently, 11 nonprofit CRCs serve the entire state; they served more than 14,000 caregivers in FY 2001–02.

The DSS administers the sizable statewide In-Home Supportive Services (IHSS) program, launched in 1973. That program receives significant state general funds, county funds and federal Medicaid dollars (through the Personal Care Services Program). IHSS provides 25 home care services, including respite care, to elderly individuals and people with disabilities who need assistance to remain in their homes. More than 274,000 clients were served in 2001, of whom about 60% were 65 years or older.

The DHS administers the California Partnership for Long-Term Care; California is one of four states in the country to have implemented a public/private partnership to provide long-term care insurance. Californians have the option to purchase an approved long-term care insurance policy that includes an asset protection component and respite care benefits for family caregivers. Under the program, for each dollar that a consumer's policy pays out in benefits, the consumer may shelter a dollar of assets for Medicaid eligibility purposes.¹⁷

^b In California, a "joint powers agreement" is a quasigovernmental body composed of local government officials, generally from several different counties, that have joined together.

The DHS also oversees nine sites for the diagnosis and treatment of Alzheimer's disease, known as Alzheimer's Disease Research Centers. These state-sponsored university medical centers provide clinical assessments of individuals with memory problems, family conferences and treatment planning following the evaluation, support groups for caregivers and training and education for professionals and family caregivers.

In 2002, the DSS was awarded a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS). The DSS will use the approximately \$1.4 million to:¹⁸

- ❖ Develop training, educational materials and other methods of support to aid IHSS consumers so that they can better understand IHSS and develop the skills required to self-direct their care
- ❖ Identify training and other support needs of IHSS providers and create materials, tools and work aids that will enable providers to improve the quality of care they provide
- ❖ Develop training and work aids to enable IHSS social workers to perform better IHSS needs assessments, particularly for disabled children and persons with cognitive and psychiatric disabilities
- ❖ Assist county eligibility workers to properly assess eligibility for disability-related programs

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT ^c

In California, several laws provide explicit recognition of family and informal caregivers. State statute has recognized family caregivers since 1979, when the first piece of legislation that laid the groundwork for the state's CRC system was enacted. In 1984, legislation replicated the CRC system state-wide. As part of the governor's *Aging with Dignity* initiative in 2000, a modest \$500 caregiver tax credit was enacted to provide at least some assistance to cope with the oftentimes high costs associated with providing care for a loved one. The initiative also included a series of long-term care "innovation" grants, training and rate increases for some formal care providers and other components. Most recently, in 2002, California passed the first paid family leave bill in the nation, expanding on the federal family and medical leave act by providing up to six weeks of paid leave (100% employee funded) for workers who need to care for a new child or a seriously ill family member.

California has historically invested state general funds in developing in-home and community-based services for older persons. Although there has been some Medicaid expansion in recent years, the focus has been on the State Children's Health Insurance Program (S-CHIP), rather than on long-term care services. Current growth has been constrained by Medicaid budget shortfalls, and by a relatively fiscally conservative governor, Gray Davis (D), whose focus has been on education and other services for children.¹⁹

^c For information on Program Background/Development on California's programs serving family and informal caregivers, see Family Caregiver Alliance's October 1999 *Survey of Fifteen States; Caregiver Support Programs: Final Report*.

Considerable fragmentation characterizes the California system, with programs administered out of various departments having different eligibility requirements, services and target populations. Many of California's publicly funded programs providing caregiver support predate the passage of the NFCSP under the Older Americans Act Amendments of 2000. The most significant program is the state-funded CRC system administered by the DMH. With the passage of the NFCSP under the Older Americans Act, another state department, CDA, began administering caregiver support with the federal NFCSP dollars. Thus, the CDA and the DMH both administer programs that support caregivers directly. The DMH's well-established CRC program focuses on caregivers of adult-onset brain diseases/disorders and dementia and operates through 11 contracts with nonprofit agencies to deliver a wide array of services, whereas CDA's NFCSP serves a more broadly defined population, consistent with Administration on Aging (AoA) guidelines, and provides funding, via a formula, to the state's 33 AAAs. In turn, the AAAs either provide caregiver support services directly or subcontract with service providers in the local community. Initially there was tension between the two programs, but at the time of the site visit, state officials from both administering departments, as well as a variety of stakeholders, reported that the two programs are increasingly working together to collaborate and to avoid—to the degree possible—duplicative administration and service delivery. The AAAs, for example, are using some of their NFCSP dollars to subcontract with many of the CRCs to provide caregiver support services.

Family caregivers also benefit indirectly through several other CDA programs and the DSS-administered IHSS. Significant CDA programs that assist family and informal caregivers are the Alzheimer's Day Care Resource Centers (ADCRC), Adult Day Health Care (ADHC), the Aged Medicaid waiver (the Multipurpose Senior Services Programs, or MSSP), Linkages (a case management program) and the Senior Companion program.

California state officials concurred that family and informal caregivers are explicitly recognized as a central component of the current long-term care system. One state government respondent tied the higher recognition to the increasing number of public policymakers who are facing their own caregiving issues. While programs still tend to focus on the beneficiary for targeting services, the respondent saw an increasing recognition of the informal support network within all of California's programs. Stakeholders did not agree. One asked, "Are we all agreeing that there *is* a comprehensive long-term care system that caregivers can be a central component of?" Another said that there is some recognition, but so much that family caregivers do and pay for is taken for granted, and that it is a real frustration. The fact that the IHSS program pays family caregivers is positive, the respondent pointed out, particularly since other states do not have programs of this magnitude. One stakeholder observed that significantly greater funds would be invested in respite care, family training and other supports if caregivers were truly recognized.

Most rewarding: Key informants noted that the significant influx of funding for caregiver support services has been most rewarding. The secondary impacts of the NFCSP have also been rewarding, CDA officials said, providing the example that the state's Health Insurance Counseling and Advocacy Program (HICAP) has a caregiver component.^d Respondents felt that the focus on caregiving would

^d California was one of 13 states to start a state-funded HICAP program before federal funds were made available from CMS in 1992.

bring more people together, encouraging them to get out of their “silos” to work more collaboratively and serve a broader array of individuals. Informants from the DMH pointed to the quality of care being delivered by the CRCs as most rewarding. The most rewarding aspect IHSS officials identified in their program is that it has worked to keep people at home.

Biggest challenge: The range of challenges cited by key informants reflected the different stages of development among California’s caregiver programs. For the NFCSP, respondents from CDA identified:

- ❖ Procurement of the state match; AAAs are concerned that they may not be able to come up with the funds
- ❖ Implementation of the program and the distribution of funds in a reasonable time frame
- ❖ The “tug” between state standards and local flexibility
- ❖ The demands and complexities of implementing a new program that represents a major paradigm shift to serving the caregiver, rather than directly serving the care recipient (i.e., the older person)

DMH officials cited funding issues as the biggest challenge, saying that there is so much need and not enough money, with a long waiting list of people who need services. From the DHS perspective, the biggest challenges were that the Aged Medicaid waiver was not yet available in all counties and that providing all the necessary home and community-based services while still remaining cost neutral was difficult. The complexity in administering the IHSS program was the biggest challenge identified by DSS informants.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—California’s NFCSP received \$10.8 million in federal funds. That sum represents 8.8% of the overall CDA budget. In FY 2002, California received about \$12.6 million for the NFCSP. Exhibit A shows funding levels for other CDA programs that provide some caregiver support services.

Exhibit A. FY 2001–02 California Department of Aging Program Expenditures

	State General Funds	Federal Funds
ADCRC	\$4.2 million	\$355,000
ADHC	\$1.3 million	\$1.4 million
Linkages	\$8.1 million	none
MSSP ^e	\$833,000	\$879,000

For FY 2001–02, the DMH expended \$11.7 million in state general funds for the CRCs. While that sum approximates California’s federal NFCSP funding, it is a small proportion of DMH’s overall budget of \$2.13 billion.²⁰

^e These funds are for state operations. MSSP also receives significant “local assistance” provided by DHS. For FY 2001–02, DHS provided \$38.5 million.

For FY 2001–02, the IHSS program had a state general funds allocation of \$72.4 million, which represents about 2.5% of the total DSS budget.²¹ Key informants noted that counties contribute another 17% for IHSS. The nonfederal portion (referred to as “residual”) represents 20% of IHSS funding, according to informants; Medicaid covers the other 80%. California maintains a residual program, in large part, so that spouses or parents can be paid providers of IHSS, which Medicaid rules do not allow.

For FY 2001–02, the total cost of services under the Aged Medicaid waiver (MSSP) in California was \$40.2 million.

California can expect to receive \$25 billion in tobacco settlement revenues over the next 25 years.²² The settlement revenues are divided as follows: 50% to the state, 40% to the counties and 10% to the state’s largest cities of Los Angeles, San Diego, San Francisco and San Jose. California has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid, although not specifically to expand home and community-based care. For FY 2002, the governor allocated \$170 million for Medicaid, a smaller proportion than originally planned.²³ In response to the state’s growing fiscal crisis, the governor instead dedicated more tobacco settlement monies to the state’s reserve account.

Major fiscal challenges await California as state leaders struggle to address the approximately \$24 billion budget shortfall. Stakeholders and state officials alike saw California’s budget situation as a crisis state. One state official called it “catastrophic” and “unprecedented;” another said it was “dismal.” Stakeholders characterized the budget situation as “dismal and likely to remain grim for two to four years” and “bad...extremely bad.”

At the time of the site visit, few state officials reported major cuts to their programs and services. One respondent, however, emphasized that innovation was likely to suffer and that, with the threat of state job cuts, justifying new staff for program development was a challenge. Administrative cuts for IHSS at the local level had been proposed, DSS officials noted. (Social workers, employed by County Departments of Social Services, do the assessments, authorize services and sometimes assist clients in hiring and overseeing individual providers.) With regard to the NFCSP, officials said that it would be challenging to come up with the required NFCSP matching funds, which currently must come from the CDA budget. In 2001, California used a series of innovation grants from the governor’s *Aging with Dignity* initiative that had been awarded to some of the AAAs as the source for the required match. With the innovation grants no longer available and with no new state general funds allocated, CDA officials reported that some AAAs were very worried that they would be unable to come up with the required match.

PROGRAM ADMINISTRATION

CDA officials see their agency's role in the development and implementation of the NFCSP as one of planning, policy development, administration, coordination, priority setting and evaluation of all state activities related to the objectives of the program. In turn, they view the AAAs as "having a far-reaching mandate for program administration, planning and coordination." As one respondent put it, "AAAs are responsible for the development of service systems that include not only program components directly administered by the AAA, but also those administered by other agencies." Although the CDA has focused on developing state standards, one stakeholder indicated that the flexibility provided to the AAAs means inconsistency across Planning and Service Areas (PSAs) in terms of services, assessment and reporting requirements. In this regard, CDA officials commented that the balance between statewide standards and local flexibility is a delicate one and thought the issue would evolve as program implementation continued.

Publicity efforts for the NFCSP are mainly being conducted by the AAAs through newsletters, billboards, public service announcements and cable television program appearances. Innovative "info vans" are providing mobile outreach to caregivers, which is particularly useful in rural areas, CDA respondents pointed out. One stakeholder characterized the vans as "Information and Assistance on wheels." Currently, 24 AAAs operate a total of 35 vans, most of which have been purchased directly by the AAAs.

The DMH respondents identified their role as a collaborative one involving the CRC Association (made up of the 11 CRC programs) and the SRC. The 11 CRCs administer the program at the regional level, and the SRC provides statewide coordination and technical assistance.

The DSS is the administering agency for the IHSS program and is responsible for statewide policy and the appeal process. At the local level, counties carry out day-to-day operations and policy implementation and are responsible for establishing and determining eligibility and authorizing services. Respondents underscored the increasing importance of Public Authorities, California's regional municipal governing bodies, as well. The DSS engages in many activities, with a focus on maximizing federal Medicaid reimbursement.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for California's NFCSP mirrors federal requirements under the Older Americans Act: It is for family or informal caregivers of any age who provide care to persons 60 years or older and for caregivers ages 60 or over who are caring for children age 18 or younger.^f For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or two instrumental activities of daily living (IADLs). The family caregiver is considered the client in the program.

^f Including caregivers 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

Uniform client assessment standards are not used in the NFCSP. The CDA is working to develop such standards for the NFCSP, possibly refining the assessment tool that they use for the Aged Medicaid waiver (MSSP) and the Linkages program, with the hopes of having one consistent tool used for all three programs. State officials noted that they also have consulted with the state's CRCs on the use of their caregiver assessment tool in these programs.

The DMH has uniform assessment standards across the 11 CRCs; the CRCs all utilize the same in-home caregiver assessment tool. For the CRC system, caregivers of adults (ages 18 and over) with adult-onset cognitive impairments are eligible for services. There are no income eligibility requirements. The family caregiver is considered the client in the program.

Both the IHSS and the Aged Medicaid waiver programs have uniform assessment standards, although each uses a different instrument. In both programs, the care recipient is the identified client. DSS officials noted that the IHSS assessment instrument, which collects data that become part of the state's Case Management Information and Payroll System (CMIPS), has no questions about family and informal caregivers. Informal care is taken into account in the authorization of paid services for the care recipient. Informal care is identified as an "alternative resource" available to the care recipient. Within the Aged Medicaid waiver, state officials indicated that the informal care provided by family caregivers does not have a tremendous impact; because many Medicaid waiver clients also use IHSS services, however, the amount of informal care is considered in authorizing personal care and other services.

Eligibility for the Aged Medicaid waiver is consistent with federal functional eligibility requirements: Enrollees must meet medical criteria for Medicaid nursing home level of care. For the IHSS program the care recipient must be at least 65 years of age, blind or disabled and eligible to receive Supplemental Security Income (SSI). Income eligibility standards, known as "share of cost," are also somewhat flexible in the IHSS program. Share of cost allows those whose income is above the SSI threshold to maintain eligibility for the programs, provided they make a contribution based on both income and amount of authorized services. Generally speaking, share of cost provides the greatest assistance to those whose income is not substantially above the income limits and who have a high level of need.

SERVICES

Although some of California's AAAs provide services in all five NFCSP service categories, each AAA is not required to provide every service. AAAs may provide services directly or through a subcontract with other providers. The availability of services depends upon the AAA's particular community and the needs identified through the area planning process. CDA respondents indicated that they had mapped a "service matrix" to track the various services that each AAA offers. Services include outreach, community education, information and assistance, comprehensive assessment, case management, transportation, assisted transportation, counseling, caregiver support groups, caregiver training, respite care, minor home modification, placement, homemaker and chore services, home security and safety, visitation, assistive devices, home-delivered meals, legal assistance, peer counseling, translation services and income support/material aid. Many AAAs subcontract with a CRC for some services. Officials of the CDA report that some AAAs may be utilizing county mental health department staff to perform assessments.

Whereas the NFCSP does not impose a cap for respite services, individual AAAs may do so if they choose. None has, to the knowledge of the CDA respondents. State guidelines allow for in-home, adult day services and for overnight and weekend respite, but some services may not be available at the local level because of worker and budget shortages. AAAs have the flexibility to allow caregivers to “bank” respite services.

The CRC system offers a comprehensive range of family support options in every region of the state. Services include specialized information and assistance; in-home assessment; family consultation and care planning; family meetings; individualized, group or family counseling; psychoeducational groups; support groups; legal and financial consultation with attorneys; education and training; and an array of respite options. The CRC system has a \$3,600 yearly cap for respite services. Key informants indicated that the cap was set because of budget constraints and as a way to keep the waiting list moving. Respondents also indicated that the cap helps consumers count on and plan around a set amount of money. In-home (both agency-based and with independent providers), adult day services and respite weekends (including camps and group respite) are some of the options available under the CRC program. Consumers may “bank” respite services for 12 months.

Under the Aged Medicaid waiver (MSSP), family caregivers may benefit from respite services, home modifications, education and family training, and no stated cap exists for respite service. Covered respite services include in-home respite assistance, adult day health services, overnight in a family and hospice-based respite for those with terminal illnesses.

The NFCSP and CRC system are California’s programs with the explicit goal of providing support to family and informal caregivers, other publicly funded programs also offer services that include some measure of caregiver support. These programs, along with the administering agency, are detailed below.

Exhibit B. Services for California Family Caregivers by Publicly-Funded Program

	Program	Respite	Support Groups	Caregiver Training & Education	Home Modifications	Chore or Personal Care
CDA	NFCSP	Yes	Yes	Yes	Yes	Yes
	ADCRC	Yes	Yes	Yes	No	No
	ADHC	Yes	No	No	No	Yes
	Aged Medicaid Waiver	Yes	No	No	No	Yes
DSS	IHSS	Yes	No	No	No	Yes
DMH	CRCs	Yes	Yes	Yes	No	Yes

Major services needed by caregivers: Medicaid, IHSS and DMH officials cited respite care as the major service needed; DMH respondents added that the assessment with family consultation usually lead to the provision of respite care services. Respite has been the highest-funded service category under the NFCSP. Although respite services are commonly seen as “the most vital,” CDA officials reported that “some providers suggest this service goes unused because caregivers who wait a relatively long time before seeking formal assistance with some tasks, and in the early stages of caregiving, don’t require formal respite.” Thus, CDA staff also noted the importance of recognizing the need for assistance and getting access to services. Most stakeholders identified respite as the major service needed. One stakeholder indicated that family caregivers might identify respite as the major service needed, but in fact family consultations are more important because the resulting plan of care would better equip a caregiver to handle a situation. Support groups, caregiver education and training and assistance in finding formal care providers were identified by stakeholders as services needed by family caregivers.

Table 2. Family Caregiver Support Services in California

Program	California NFCSP	Caregiver Resource Center System(CRC)	In-Home Supportive Services(IHSS)	Aged Medicaid Waiver(MSSP)	Alzheimer's Day Care Resource Center	Adult Day Health Care
State Administrative Responsibility	California Department of Aging	California Department of Mental Health	California Department of Social Services	California Department of Aging	California Department of Aging	California Department of Aging
Local Service Delivery	AAAs ^a	Caregiver Resource Centers (statewide system)	County welfare Departments, Public Authorities and contract providers	Local service providers	AAAs	DHS and local service providers
Funding Source	Older Americans Act, Title III-E	State general funds	State general funds, Medicaid Title XIX & Title XX, Block Grant funds, county funds	Medicaid ^b 1915 (c) waiver, state general funds	State general funds	Medicaid, state general funds
Expenditures FY 2001–02	\$12.6 million	\$11.7 million	\$72.4 million	\$40.2 million	\$4.6 million	\$1.4 million
Client Population	Family & informal caregiver	Family & informal caregiver	Care recipient	Care recipient	Family & informal caregiver & care recipient	Family & informal caregiver & care recipient
Eligibility Criteria:						
Age	60+ care recipient Family caregivers of any age of persons age 60+ ^c	18+ care recipient Family caregivers of any age	65+ care recipient	65+ care recipient	None	18+ care recipient
Monthly Income	None	None	SSI-eligible	300% of federal poverty rate	None	300% of federal poverty rate
Assets	None	None	\$2,000	\$2,000	None	\$2,000
Functional Ability	For all support services except access and information, care recipient must have at least 2 ADLs or IADL needs	Adult-onset cognitive impairment	Blind or disabled	Nursing home level of care	Dementia diagnosis	Frail, elderly and impaired adults

a AAAs = Area Agencies on Aging.

b In California, Medicaid is referred to as Medi-Cal.

c Also caregivers 60+ providing care to a person with developmental disability or a grandparent caregiver raising a child.

Table 2. Family Caregiver Support Services in California (continued)

Program	California NFCSP	Caregiver Resource Center System(CRC)	In-Home Supportive Services(IHSS)	Aged Medicaid Waiver(MSSP)	Alzheimer's Day Care Resource Center	Adult Day Health Care
Uniform, Statewide Caregiver Assessment	No	Yes	No	No	No	No
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^d	Information Assistance In-home assessment Family consultation Care planning Family meetings, individual & group family counseling Psychoeducation & support groups Legal & financial consultations Education, training Link2Care Internet Range of respite options	Respite care Chore or personal care	Respite care Chore or personal care	Respite care Support groups Caregiver training and education	Respite care
Respite Cap	Varies by AAA	\$3,600/year	Yes 8 hours/week	No	No	No
Consumer Direction	Yes ^e	Yes	Yes	No	No	No
Family Caregivers Paid as Respite Providers	Permissible but not utilized by the AAAs	Yes	Yes	No	No	No

^d Within these categories, AAAs provide a range of services including transportation, minor home modifications, homemaker and chore services, assistive devices, home delivered meals, legal assistance, peer counseling and other services.

^e CDA has authorized the use of consumer direction. At the time of the site visit, no AAA offered this option, however.

CONSUMER DIRECTION

Although the NFCSP permits consumer direction through a cash benefit, none of California's AAAs have taken that approach in the initial implementation of the program. CDA respondents indicated that the AAAs have not had time to establish auditable administrative procedures that would be needed in order to implement a consumer-directed option for families. In contrast, the CRC system administered by the DMH has consumer direction as a central tenet of the program. The CRCs' family consultants develop the plan of care with the consumer (i.e., family or friend) out of a menu of services. For those family caregivers who prefer in-home respite, families can choose one of two mechanisms: the vendor in-home respite program (i.e., agency-based), in which caregivers receive vouchers to purchase services through home care agencies under contract with the CRC; or the direct pay respite program (i.e., consumer directed), whereby caregivers are given vouchers to hire and manage their own respite workers. The agency-based in-home respite program is available from all 11 CRCs; nine of the 11 CRCs also offer the consumer-directed "direct pay" option and allow family caregivers to hire their own family, friends or neighbors to provide respite care.

Although the traditional Aged Medicaid waiver (MSSP) does not offer a consumer-directed option, the IHSS program administered by the DSS does, and that option is widely available and utilized. The IHSS receives funding from both the optional Medicaid personal assistance benefit and state general funds and, with regard to Medicaid, is authorized through a state plan amendment rather than through a home and community-based waiver. California places no state restrictions on the hiring of family members as IHSS workers, and by utilizing state funds, it allows all family members (including parents and spouses) to be paid care providers. An estimated 43% of IHSS providers are relatives of the care recipient.²⁴ The consumer-directed option, known in the state as the individual provider mode of delivery, is available in all 58 counties. In contrast, the contract agency mode (i.e., home-care agency model) is available in only 12 California counties. IHSS officials pointed out that many of the consumers they serve also get services under the state's Aged Medicaid waiver, so in effect, IHSS functions as the Medicaid waiver's consumer-directed option.

QUALITY ASSURANCE AND EVALUATION

The CDA has four oversight functions to evaluate the NFCSP, including budget review and approval, area plan review and approval, on-site monitoring and analysis of program data. The state currently collects a variety of demographic data on NFCSP consumers, including gender, age, race/ethnicity, marital status and employment; it also tracks relationship between caregiver and care recipient, multiple caregiving, poverty, whether the caregiver lives alone and whether an Adult Protective Services (APS) referral is involved. The CDA currently uses a paper data-reporting system. State officials plan to continue the "temporary" paper system to allow the program to remain fluid, to reduce the burden on AAAs and providers and to make it easier to adapt to changes in federal reporting requirements. The current system is an aggregate system, which is consistent with AoA reporting requirements. The CDA believes that a move toward a client-level system would allow for cross tabulations of variables and enable the CDA to perform more sophisticated data analysis. For now, the data will have to "speak for itself," CDA respondents said.

The CDA has contracted with the University of California at Berkeley to develop a profile of caregivers and care recipients in California using a random-sample, statewide telephone survey of adults who are providing care to a person age 50 or older and focus groups. Data being collected include:

- ❖ Social and demographic characteristics
- ❖ Caregiver and care recipient health and functioning
- ❖ Care provided by caregivers and caregiver services
- ❖ Support received and the impact of caregiving on the caregiver

Follow-up telephone interviews will focus on a variety of issues, including the caregiver's extent of knowledge about local caregiver support programs, utilization patterns, program effectiveness, predictors of service use and nonuse, unmet needs and client satisfaction. The university will also work with CDA and selected AAAs to examine the impact of caregiver programs on caregivers and care recipients.

At the time of the site visit, the uniform caregiver assessment instrument used by the DMH's CRC system was being revised, and a new automated client-tracking and data collection system was in the process of being implemented to assist with planning, service scheduling and other needs. The CRCs collect data on caregiver outcomes. The SRC also plays a significant role in data collection for the CRC system, tracking and profiling information on caregivers and care recipients in the program, service utilization, expenditures, hours of respite providers and major needs identified by family caregivers within the CRC system. The SRC prepares quarterly and annual reports for DMH.

Within the Aged Medicaid waiver (MSSP), data collected on family and informal caregivers are limited to basic demographic information: name and telephone number, relationship to the care recipient and hours available to provide care.

Under the IHSS program, data collected on family caregivers are also limited to basic demographic information such as age, ethnicity and relationship to the care recipient. The system, known as the Case Management Information and Payroll System (CMIPS), is automated. Although the fiscal intermediary can run special reports, there is a time lag in getting results. To evaluate the program, IHSS looks at county and statewide service utilization aggregates and conducts site visits (by state DSS staff) that include client satisfaction surveys.

SYSTEMS DEVELOPMENT

California has historically had a complex and fragmented long-term care system, administered by numerous state agencies. Adding to the confusing and complicated structure and administration, many of the state programs are operated through local government agencies and private nonprofit organizations, creating an even more confusing array of eligibility requirements and different services and service delivery options that pose barriers to consumers who attempt to access help in their communities.

“We’re a little bit ahead of other states because of the high level of interest with the legislature and governor paying attention to how we develop a family caregiver support program,” said one state official, referring to the statewide system that was in place pre-NFCSP. The official went on to say that when the NFCSP funding came in, there was a great deal of interest from AAAs, the legislature

and other aging and long-term care advocates to look at caregiving from a new, family approach, which is a little different from other Older Americans Act programs that focus on the care recipient. The CRC system was viewed as a positive program but limited in the population it serves; the new program allowed the state to serve a broader group beyond the population of caregivers of adults with cognitive impairment (e.g., Alzheimer's disease, stroke, traumatic brain injury). The state legislature, through budget-control language, has assured no duplication of services at the local level.

In terms of coordination of caregiver support services at the state and local levels, informants had divergent views. The CDA officials interviewed believed that state-level coordination exists and identified existing federal requirements as a barrier to a greater level of integration and coordination. Other state officials were less optimistic and believed that caregiver support services were not highly coordinated in the state or well integrated into California's other home and community-based care programs. Stakeholders representing a variety of agencies and groups felt that there was little state-level coordination and characterized the CDA, with the implementation of the NFCSP, as having delegated coordination to the AAAs at the local level, irrespective of the "already-in-place" state-funded CRC system administered by DMH.

The CDA characterized the NFCSP implementation process as methodical and thoughtful, and one that included "everyone" at the table. In view of the initial skepticism about giving the funding to the AAAs, rather than to the CRCs, they felt they had had to "climb uphill" and defend the local process, rather than step in and push for uniformity across the AAAs in their request for proposals (RFPs). State officials commented that although they hadn't wanted to "reinvent the wheel" with the NFCSP (referring to the preexisting CRC program), they had first had to make sure that what was already in place was "the right wheel." "Development of a seamless system of services that is consumer-focused is always a goal and remains a significant undertaking," one respondent said. "With the implementation of the NFCSP, every effort is being made to avoid creating an additional 'silo' program." Methods being used to assist in this integration are heavy reliance on the AAA's local planning process; maintenance of maximum local flexibility, consistent with the AoA direction; and the development of projects designed to specifically integrate the program into existing long-term care programs (e.g., integration of the care management assessment tools with caregiver assessment tools).

The AAAs coordinate caregiver services at the local level through the AAA's planning and contracting process. The CRC system also coordinates services at the local level, through the regional CRCs, with the SRC assisting the system to develop statewide standards and resources, such as a new information technology system. Some AAAs subcontract with CRCs to build on the infrastructure in place and to enhance coordination. For example, the Orange County AAA subcontracts all of its NFCSP service funds with the existing Orange CRC to expand support for caregivers in Orange County.

Most respondents mentioned the Long-Term Care (LTC) Council, within the CHHSA, as the body that is coordinating caregiver support services across state departments. Several stakeholders pointed out, however, that the council's mission is much broader than just caregiver support and that caregiver support has not been a major issue addressed by the council.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

The LTC Council is composed of the heads of all relevant departments (Developmental Services, Health Services, Rehabilitation, Mental Health, Social Services, Aging, Veterans Affairs and the Office of Statewide Health Planning and Development). It is the main body charged with *Olmstead* planning and implementation. Created in 1999 through legislation (A.B. 452), the council’s mission is to “provide state-level leadership in developing a coordinated long-term care system that includes a full array of services, that promotes personal choice and independence while also assuring fiscal responsibility and equitable access to all long-term care consumers.”²⁵

The LTC Council has issued a values statement that includes:

- ❖ Honoring choice, dignity, independence and quality of life
- ❖ Seeking input from consumers, family caregivers and the community
- ❖ Supporting caregivers
- ❖ Making sure that a long-term care workforce is available
- ❖ Encouraging flexibility and innovation
- ❖ Providing education on the potential need for long-term care and on viable options available to help individuals plan ahead for that potential need

The LTC Council has set up six work groups, or subcommittees, to focus on various issues. The council is working to identify barriers to mental health coverage for persons with Alzheimer’s disease and other forms of dementia and ways to overcome those barriers. The CHHSA has also developed an *Olmstead* planning and work group and has offered limited reimbursement for travel expenses necessary for consumers to enable them to participate. In 2002, CHHSA planned a series of *Olmstead* forums throughout the state to provide input into the state’s *Olmstead* plan documents.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?” Although responses were mixed, no key informant saw the priority as greater than “medium.” Most state officials agreed that the priority on caregiver support was “medium,” although DMH respondents saw it as “low - medium.” Stakeholders’ assessments varied, with three indicating “low,” one “low - medium” and two “medium.”

Number of Key Informants	Priority on Caregiver Support
3	→ Low
2	→→ Low-Medium
5	→→→ Medium

Benefits and challenges: CDA respondents felt that it was too early to predict the impact of the NFCSP. Other California case study respondents identified a variety of benefits their programs offer to family caregivers:

- ❖ Assessment with family consultation and respite (DMH)
- ❖ Information and support—the overall support available from persons who are knowledgeable about the situations of caregivers (DMH)
- ❖ Flexibility in maintaining individuals in a home setting (DHS)
- ❖ Especially for poor families, the ability to stay with families and give back to them by providing care (DSS)
- ❖ The natural knowledge of family, friends and neighbors who have long-term relationships with the individual who needs care and can provide better services than could a stranger (DSS)

When asked to identify the three main challenges for implementing family caregiver support programs in California, state respondents noted the following:

- ❖ Limited federal funding (DHS, DMH, DSS, CDA)
- ❖ Lack of flexibility with federal funds, which keeps states from doing what needs to be done (DHS)
- ❖ Lack of policies that require some responsible party to keep family caregiver support out in front, across all departments, reminding all service providers involved in long-term care programs (DHS)
- ❖ Duplicative administrative structures for caregiver support programs (DMH)
- ❖ A requirement that programs serve the entire state, which discourages piloting innovative measures (DSS)
- ❖ Shortages of staff to implement programs (CDA)
- ❖ A short time frame for program implementation (CDA)

Major lessons learned:

- ❖ Developing the family approach enhances the way all CDA programs and services are delivered. “We learned as a department that caregiving is a family issue, not in a vacuum,” said one CDA informant.
- ❖ Integrating all caregiver support services poses a big challenge. It is important to avoid developing yet another categorical program, when what is needed is a coordinated system of support services that reach the caregiver and other beneficiaries in the caregiver’s informal network.
- ❖ “People who do the caregiving and people in the field are phenomenal,” one DMH official said. “They have incredible strengths and they don’t get enough recognition for their work, which is largely a labor of love.”
- ❖ Flexibility at the state level, as well as at the service levels, is important. “Listen, be flexible and be creative in finding options to fill needs. Nothing is absolute.”

- ❖ The family caregiver can be the client. It is important to give value to family care and the spiritual, intellectual and emotional health of family caregivers.
- ❖ Listening is important. “If you just listen to people, they wander through their problems and often come up with solutions themselves,” said one respondent.
- ❖ The social work model—that of supporting the family unit—has worked well in the IHSS program because it allows clients the right to choose their providers while remaining in their own home community, respondents from the IHSS program at the DSS said.

Opportunity for expanding caregiver support: Respondents were mixed in their views as to whether state-funded programs to support family caregivers would be expanded in California in the next three to five years. Respondents from CDA thought expansion would occur, dependent upon the pace of economic recovery and driven by the *Olmstead* plan. Another key informant said that expansion would not be a surprise because family caregiving continues to surface more and more. Officials from IHSS hoped to improve wages and benefits for paid family caregivers; they cited budget concerns as the “limiting factor,” however. IHSS respondents said that recent legislation (A.B. 925) signed into law creates a significant infrastructure intended to increase job opportunities for Californians with disabilities by allowing IHSS to be extended to the workplace. DMH officials felt that all was contingent upon the budget and upon fixing structural problems, saying that the data and information available from the CRC program, along with *Olmstead* planning, should lead to expansion opportunities.

Recommendations for other states: State officials in California had several recommendations for other states:

- ❖ Listen to family caregivers when designing programs, but get beyond “the stories” to hear the real issue, then figure out how to deal with it in the bureaucracy (DHS).
- ❖ Take a collaborative rather than an adversarial approach. Work across departmental lines: See what other state agencies have in common with yours, and work together; collaborate and partner with other existing agencies administering related programs (DHS, DMH and CDA).
- ❖ Seek a stable, reliable funding source (DMH).
- ❖ Don’t reinvent the wheel. Look at other states with effective caregiver support programs and build on those (DMH).
- ❖ Adopt a creative/flexible approach; preserve a broad interpretation of the law (CDA).
- ❖ Place a high value on the role that family caregivers can play; expand home-care programs so that family and informal caregivers can be paid to provide services (DSS).

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