CALIFORNIA'S FAMILY CAREGIVER SUPPORT SYSTEM:

FINDINGS AND RECOMMENDATIONS

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1. Characteristics of Family Caregivers

Based on the Statewide Survey of California Caregivers, a telephone-administered interview with a randomly-selected sample of 1,643 state residents who provide care to someone age 50 or over, it is estimated that 16% of all California households (with a telephone) contain at least one caregiver for someone age 50 or over. This translates to a minimum of 1,803,995 caregiver households out of the 11,502,870 households in California.

California caregivers have an average age of 51 years, slightly older than caregivers nationally. Three-fourths are women, 60% are married, and 31% have children under the age of 18 living at home (as compared with 41% nationally). Sixty-one percent are White/Caucasian, 25% are Hispanic/Latino, 6% Black/African American, and 5% Asian. Most caregivers were born in the US (86%), but a notable number (6%) report Mexico as their country of origin. About half of California's caregivers are employed – 35% full-time and 14% part-time. Three-fourths of caregivers (74%) evaluate their health as good, very good, or excellent, with 26% indicating that their health is fair or poor; 28% report health or emotional problems.

Care recipients range in age from 50 to over 100, with a mean of 77 years. Seventy percent are women, half are widowed, one-third are married, and 10% are divorced. Thirty-five percent live with the respondent, while another third live alone, 6% live in an assisted living facility, and 3% live in a nursing home. Thirty-six percent suffer from severe memory problems or dementia, 36% have mental health problems, and 56% have three or more physical health conditions.

2. Impact of Caregiving

While caregiving can prove to be a positive experience for many individuals, it also can have negative impacts on caregivers' health and well-being. One-third of caregivers report high levels of emotional stress (a rating of "4" or "5" on a 5-point scale) associated with providing care, while 18% report high levels of physical strain, and 15% report high levels of financial hardship. More than one-fifth report suffering either physical or emotional problems as a result of their caregiving responsibilities, and one-fourth report sleep disruptions. More than one-fifth have no one they can go to for support and understanding regarding their caregiving situation.

3. Characteristics of Grandparents Caring for Grandchildren

One-half of grandparent caregivers are age 60 or above. Slightly less than three-quarters of grandparent caregivers in California are married (73%); almost two-thirds (62%) are women. Over half (53%) are in the workforce, and a substantial number (16%) are poor. In California, 12% of all African-American children, 11% of Hawaiian and Pacific Islander children, and 10% of Native American children live in grandparent-headed households, as do 7-8% percent of Hispanic, mixed race, and "other race" children. This compares with only 5% of White and Asian children.

4. Impact of Kin-Caring on Personal Well-Being

Grandparents raising grandchildren are at significantly increased risk for depression, functional limitations and financial difficulties. They frequently report chronic health problems, and 56% have limitations in one or more self-care activities. Grandparents raising grandchildren often report substantial declines in marital satisfaction, as well as decreased socialization with friends and family, and an inability to continue participation in church and senior center activities.

5. Vulnerable Caregivers

California caregivers who experience the highest levels of financial hardship, physical strain, and emotional stress are more likely to be female, Hispanic, low income, and in poor health. They are more likely to care for someone with mental illness/emotional problems, dementia/memory problems, behavioral problems, or stroke or paralysis. Furthermore, they are more likely to report that the caregiving situation has created family conflict and has been a significant hardship for their families.

B. Existing Resources

1. State Resources for Caregivers

California has a vast array of potential resources for family caregivers. Programs for caregivers are administered by several state departments within the Department of Health and Human Services (DHHS), including the following: the Department of Aging, the Department of Developmental Services, the Department of Health Services, the Department of Mental Health, and the Department of Social Services. Each of these state departments channels funding from various sources to a range of public, private, and not-for-profit service-providing organizations.

2. Local Caregiver Resources

According to information provided by Area Agencies on Aging (AAAs) and collected via the internet, the support services most likely to be available for caregivers include the following: caregiver information, counseling, and referral provided through the Caregiver Resource Centers; daytime respite offered through the various Adult Day Programs; and, general community social service programs such as support groups, senior centers, and faith-based organizations.

Caregivers, on the other hand, are most likely to turn to health care providers (especially for education, information, and counseling), followed by AAAs and other public entities (for financial advice and information about services), residential care providers (for overnight and in-home respite), professionals (for legal and financial advice), other agencies and community-based organizations (for information about services), and religious organizations (for pastoral counseling and peer group support).

In all, 70% of California caregivers report receiving one or more support services from a community agency or other formal service provider. White non-Hispanic and African American caregivers are about twice as likely to use formal services, as are Latinos, Asian Americans and Pacific Islanders.

3. Resources for Grandparent Kin-Carers

The service network that exists for older adults caring for young family members is smaller than the array of services currently available for caregivers of older adults. The

California *Kinship Support Services Program (KSSP)* provides one-on-one peer mentoring, parenting education, support groups, case management, health assessments, nutrition counseling, transportation assistance, emergency tangible goods, and family activities. In addition to the KSSP network, most support services for family caregivers of children consist of local community social service programs and support groups, often funded privately through community or faith-based organizations.

C. Unmet Needs

1. Needs of Family Caregivers

Unmet needs identified most frequently by caregivers include information about where to find and how to access services, training and education about care provision, and financial and legal assistance. Other needs identified by AAAs, but less frequently by caregivers themselves, include respite care, transportation, and culturally and linguistically appropriate services.

Lack of knowledge of where to obtain assistance is the primary impediment to caregivers' use of desired services. Other reasons often given for not using desired services include the cost of services, the reluctance of the care receiver to use the service, the sheer lack of availability, and poor quality of service.

2. Needs of Grandparent Kin-Carers

Grandparents have a variety of service needs, in order to cope effectively with the demands of caring for a young child. These include social support, financial assistance, health insurance, legal assistance, and housing. However, grandparents frequently delay or fail to seek formal assistance for their own needs, despite their increased risk of physical and mental health problems.

D. Local Needs Assessment Activities

AAA s utilize a variety of strategies to assess the needs of caregivers in their local Planning and Service Agencies (PSAs), including surveys, focus groups, public meetings, input from community representatives, and administrative data. Although caregiver-specific surveys have the potential to provide the most accurate and useful information about caregivers in the PSA, few AAAs report collecting and analyzing data from sample surveys that are specific to family caregivers or grandparent kin-carers.

A critical component of the caregiver needs assessment process is development of a profile of the basic demographic and social characteristics of all caregivers in a PSA, including those who do not currently utilize Title III-E services. This information can best be obtained through a household survey of a representative sample of caregivers, preferably administered every few years. The California Statewide Survey of Caregivers provides a baseline upon which future surveys can be developed.

E. Characteristics and Limitations of California's Caregiver Support System

California has a wide variety of actual and potential supports for caregivers; however, the lack of local and statewide coordination contributes to a great deal of fragmentation and duplication. Programs often differ with regard to their eligibility requirements, target populations and services, typically based on historical patterns rather than a rational approach to planning. Some groups apparently are served by substantial resources (e.g., caregivers for persons with dementia, especially those in certain areas), while other groups may be less well-served (e.g., caregivers for persons with mental illness).

F. Vision for a More Effective Caregiver Support System

1. <u>Fundamental Goals of an Effective Caregiver Support System Include the Following:</u>

- Improvements in caregiver well-being
- Improvements in care recipient well-being
- Increased public support for family care
- Increased support for caregivers by formal and informal community support structures
- Increased political support for caregiver-friendly policies and programs

Supporting caregivers requires a broad approach, incorporating multiple funding streams and diverse types of assistance. Of particular interest are the potential contributions of sometimes-overlooked resources such as health care providers, religious and communal organizations, and non-traditional information sources such as the Internet.

2. Specific Recommendations

A comprehensive caregiver support system in California requires enhancements in the following areas:

a) Public education and awareness. Public awareness campaigns designed to promote public recognition and discussion of the prevalence and realities of family care should be conducted statewide as well as locally.

b) Information and referral. Caregivers need a dedicated, statewide "1-800" number that they can call for assistance. In addition, information specialists in existing systems (e.g., AoA Eldercare Locator - 1-800-677-1116; AAA Statewide Number – 1-800-510-2020; or development of a "211" non-emergency information system) should be trained to recognize caregiving issues and refer caregivers to appropriate resources.

c) Identification and assessment. Assessment of caregiver needs and resources should be an integral part of care planning and service delivery efforts in all programs serving older adults, especially those designed to serve persons requiring home and community-based care (e.g., IHSS, MSSP, Linkages) as well as health and mental health programs serving vulnerable individuals.

d) Caregiver education and training. Education and training for family caregivers, including training in specific caregiving tasks, education about disease processes, and problem-solving and coping techniques, should be an explicit component of programs serving elderly and disabled persons, health and mental health services, and caregiver-specific support programs.

e) Support for vulnerable caregivers. Intensive intervention efforts should be targeted to vulnerable caregivers, including those who experience high stress levels, care for someone with problematic behaviors, dementia, or a high level of daily dependency, or who are poor, socially isolated, or have health problems of their own. Interventions should include a combination of individual and family counseling, support, and education, including problem-solving and behavior-management skills training, family counseling, disease-specific support groups, and respite care.

f) Education for service providers. Health and long-term care professionals and paraprofessionals should receive training regarding the identification and assessment of caregiver needs as well as information about available community resources for caregivers. A module on family caregiving should be developed for inclusion in professional training and continuing education courses in gerontology, in collaboration with professional associations and educational organizations.

g) Collaboration with employers. AAAs and local community organizations should collaborate with employers to enhance support for employees who have family care responsibilities, and to inform employed caregivers regarding the resources available to them.

h) Collaboration with health care providers and other organizations. Physician office staff, discharge planners, and other health care personnel should be provided informational materials about caregiving and to local caregiver support resources for distribution to patients and their families at critical transition points in the health care process, such as hospital discharge, nursing home admission, or the diagnosis of Alzheimer's disease. Efforts also should be made to enhance the caregiver support capacity of other community organizations and natural communities, such as churches, fraternal organizations, and other affinity groups.

i) Integrated information system. An integrated CDA-AAA caregiver information system should be developed, consisting of three components: 1) a Profile of Caregivers and Care Receivers, including local, regional, and statewide information regarding the characteristics and needs of a representative sample of caregivers; 2) a PSA-Based Client-Specific Data and Service Use Common Data Set, incorporating client-specific information on caregiver and care receiver characteristics with unduplicated counts of service utilization for caregiver support services; and 3) a PSA-Based Client Satisfaction Profile, including service satisfaction and client outcome information from a representative sample of clients using caregiver support services.

j) Target population(s). Consideration should be given to expanding current state caregiver support programs to include families caring for adults and children with all types of disabilities, and non-parental relatives of all ages who have primary care responsibility for young children.

k) Local and statewide coordination. Local caregiver planning committees should be established to improve community supports for caregivers and reduce service fragmentation and duplication. These committees should include representatives of the major local service providers for caregivers and care receivers, and their advocates. A statewide caregiver planning committee also should be convened, perhaps under the auspices of the Long-Term Care Council. The California Association of Area Agencies on Aging and the California Department of Aging should promote cross-learning among AAAs. Family Caregiver Alliance, as the Statewide Resources Consultant, should be called upon to assist local and state entities to access existing knowledge about effective practice models.

l) Funding. Federal appropriations for Title III-E should be increased or at least sustained. Greater transparency regarding current state expenditures to support caregivers would improve central planning.

m) Advocacy. Caregivers and their representatives should be actively involved in local and statewide planning activities. In addition, consideration should be given to identification of a single statewide coalition or organization charged with representing and advocating for the needs and concerns of caregivers.

n) Quality assurance. Research should be conducted to document the effectiveness of current efforts to assist caregiving families. Such evidence is essential for assuring that programs are cost-effective, and that families receive the specific types of services from which they are most apt to benefit. The Profile of Caregivers and Care Receivers, PSA-Based Client-Specific Data and Service Use Common Data Set, and PSA-Based Client Satisfaction Profile envisioned in this report are a requisite feature of any systematic statewide effort to assure the quality of California's caregiver support programs.

G. Conclusion

The basic building blocks upon which to develop a more comprehensive system of support for family caregivers in California appear to be in place. However, developing a more effective system will require collaboration and coordination among formal and informal networks, including public and private entities, as well as leadership from local and state governments.

I. CHARACTERISTICS AND NEEDS OF FAMILY CAREGIVERS

A. Family Caregivers for Older Persons

The following summary of the social and demographic characteristics of California's caregivers is based on the Statewide Survey of California Caregivers, a telephone-administered interview with a randomly-selected sample of 1,643 state residents who provide care to someone age 50 or over. The survey was conducted by the Inland Empire Research Consortium, which is made up of faculty and staff from the University of California at Riverside and California State University, San Bernardino (CSUSB). The survey findings have an accuracy rate of plus/minus approximately 3%, at a 95% level of confidence.

1. Prevalence of Caregiving in California

Based on the random sampling procedure utilized in this study, it is estimated that 15.68% of all California households (with a telephone) contains at least one caregiver for someone age 50 or over. This translates to a minimum of 1,803,995 caregiver households out of the 11,502,870 households in California. This is comparable to a 1997 national study,[2] which estimated that approximately 17% of all U.S. households with a telephone contain at least one caregiver.

2. Summary of Caregiver and Care Recipient Characteristics

Table 1 summarizes key social and demographic characteristics of caregivers in California, compared with findings from a national survey. California caregivers have an average age of 51 years, slightly older than caregivers nationally. Three-fourths are women, 60% are married, and 31% have children under the age of 18 living at home (as compared with 41% nationally). Sixty-one percent are White/Caucasian, 25% are Hispanic/Latino, 6% Black/African American, and 5% Asian; the sample resembles the state's racial and ethnic make-up, although it under-represents Asian households. Most

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[2] "Family Caregiving in the U.S.: Findings from a National Survey" by National Alliance for Caregiving and American Association of Retired Persons, 1997.

caregivers were born in the US (86%), but a notable number (6%) report Mexico as their country of origin. Three-fourths of caregivers (74%) evaluate their health as good, very good, or excellent, with 26% indicating that their health is fair or poor; 28% report health or emotional problems.

The care recipients range in age from 50 to over 100, with a mean of 77 years. Seventy percent are women; half are widowed, one-third are married, and 10% are divorced. Thirty-five percent live with the respondent, while another third live alone, 6% live in an assisted living facility, and 3% live in a nursing home. Thirty-six percent suffer from severe memory problems or dementia, 36% have mental health problems, and 88% have multiple physical conditions. Eighty-six need help “going shopping or getting to the doctor’s office,” 75% with household chores, 64% tracking financial matters, 54% arranging for care or services, and 50% with medical needs (Table 2). The care recipient activity that required the least assistance was dressing, eating, bathing, or getting to the bathroom (42%).

As seen in Table 2, 42% of the care recipients need help with the basic activities of daily living (dressing, eating, bathing, or getting to the bathroom). But many of the care-recipients need help with *several* of the other five instrumental activities of living cited in Table 2. Indeed, 49% of care recipients need assistance with four or five of those instrumental activities. Only 5% of the care recipients apparently don’t receive assistance in any of these instrumental activities, and only 11% receive assistance in exactly one of them.

TABLE 1. CAREGIVER SOCIAL AND DEMOGRAPHIC CHARACTERISTICS

Age (n = 1,597)	% in sample	% in National survey
Under 35	14%	22%
35 – 49	32%	39%
50 – 64	34%	26%
65 or older	19%	12%
Mean age	51 yrs	46 yrs
Modal age	50 yrs	

Current Marital Status (n = 1,499)	% in sample	% in National survey
Married	60%	66%
Living with partner	2%	
Separated	2%	13%
Divorced	12%	
Widowed	7%	8%
Never Married	16%	13%

Gender (n = 1,635)	% in sample	% in National survey
Female	75%	72%
Male	25%	27%

Children < 18 yrs old in household (n = 1,630)	% in sample	% in National survey
Yes	31%	41%
No	69%	58%

Highest Level of Schooling (n = 1,625)	% in sample	% in National survey
< High School grad	11%	9%
High School grad	21%%	35%
Post HS training	33%	26%
College graduate	24%	20%
Post-graduate degree	12%	9%

Race/Ethnicity (n = 1,614)	% in sample	% in National survey
White (non-Hisp)	61%	82%
Black (non-Hisp)	6%	11%
Hispanic/Latino	25%	5%
Asian	5%	2%
American Indian/ Alaska Native	1%	1%
Hawaiian/ Pacific Islander	0.2%	

Household Income for 2001 (n = 1,643)	% in sample	% in National survey
Under $10,000	9%	N/A
$10,000 - $20,000	16%	“
$20,001 - $30,000	13%	“
< $30,000 (unspecified)	2%	
$30,001 - $39,999	11%	“
$40,000 - $50,000	12%	“
$50,001 - $80,000	17%	“
Over $80,000	17%	“
> $30,000 (unspecified)	3%	“

Country of Origin (n = 1,380)	% in sample	% in National survey
United States	86%	N/A
Mexico	6%	“
Asian/Pacific Island	2%	“
Central America	2%	“
Europe	2%	“
Canada	1%	“
Other	2%	“

3. Care Provided by Caregivers

Among respondents to the Statewide Survey of California Caregivers, 73% provide assistance with shopping or getting to the doctor’s office, 55% assist with meals or other household chores, 49% assist with bill paying or other financial matters, 44% arrange for care, 37% assist with medical needs, and 29% assist with dressing or other aspects of personal care. Caregivers spend a median of 14 hours per week providing care (that is, half the caregivers spend more than 14 hours and half spend less).

TABLE 2. ACTIVITIES FOR WHICH CARE-RECEIVERS NEED ASSISTANCE, AND WHO PROVIDES THE HELP

ACTIVITY FOR WHICH CARE-RECEIVER REQUIRES ASSISTANCE		PERCENT WHO PROVIDE THE HELP FOR EACH ACTIVITY		
	% Who Need Help	Caregiver	Family/ Friends/ Neighbors	Paid Provider
Going shopping or getting to the doctor's office	86	85	36	12
Preparing meals, doing laundry, or cleaning house	75	74	33	26
Keeping track of bills, writing checks, or other financial matters	64	76	36	4
Arranging for care or services	54	82	35	8
Medical needs, e.g., taking medicine or changing bandages	50	74	30	25
Dressing, eating, bathing or getting to the bathroom	42	69	34	33

Family members and friends are the most frequently mentioned other sources of assistance for each of these activities, and they provide a median of 10 hours per week of assistance. However, one-fourth of caregivers report that there is no one else who could help their care recipient if they were unable to do so.

Paid service providers assist with care provision (e.g., dressing, preparing meals, going shopping) in about 22% of cases. The median time spent by paid service providers was 15 hours/week. Most caregivers feel that their care receiver receives “about the right amount” of assistance from paid service providers, although about one-third report that their care receiver does not get enough assistance, especially in the areas of home care, transportation, financial assistance, and medical/rehabilitation services. One-fifth of caregivers report problems with the services their care recipients receive, including problems receiving or paying for medical care, poor service quality, lack of availability when needed, and affordability.

4. Impact of Caregiving on Employment

About half of California's caregivers are employed – 35% full-time and 14% part-time. Of these working caregivers, 23% report making changes in their job status, including 13% who have reduced the number of hours they usually work, and 4% who have been forced to change jobs. One-fifth report missing work in a two-week period, including 12% who were absent at least one full day and 14% who took time off during the workday, resulting in a median of 8 hours a week of missed work.

5. Impact of Caregiving on Personal Well-Being and Family Functioning

While caregiving can prove to be a positive experience for many individuals, it also can have negative impacts on caregivers' health and well-being. One-third of caregivers report high levels of emotional stress (a rating of "4" or "5" on a 5-point scale) associated with providing care, while 18% report high levels of physical strain, and 15% report high levels of financial hardship. More than one-fifth report suffering either physical or emotional problems as a result of their caregiving responsibilities, and one-fourth report sleep disruptions. More than one-fifth have no one they can go to for "support and understanding" regarding their caregiving situation.

Despite the difficulties associated with providing care, caregivers generally report positive impacts on family life. More than one-third of caregivers report that the caregiving situation has brought their families closer, while about 70% feel that they are making a major contribution to their families, and nearly 80% feel that they are setting an example for the children in their family.

B. Grandparent Kin-Carers

1. Characteristics of Grandparents Caring for Grandchildren

One-half of all grandparent caregivers in the U.S. are age 60 or above (Fuller-Thomson et. al, 1997). The typical grandparent raising a grandchild is a White married woman living modestly but above the poverty line. Slightly less than three-quarters of grandparent caregivers in California are married (73%) almost two-thirds (62%) are women. Over half (53%) are in the workforce, and a substantial number (16%) are poor.

Although the majority of relative caregivers are White, African Americans and Latinos have a substantially greater likelihood of taking on this role (US Census/C2SS, 2001). In California, 12% of all African-American children, 11% of Hawaiian and Pacific Islander children, and 10% of Native American children live in grandparent-headed households, as do 7-8% percent of Hispanic, mixed race, and "other race" children. This compares with only 5% of White and Asian children (Minkler and Odierna, 2001).

The prevalence of grandparents caring for grandchildren varies throughout the state. In urban San Francisco County, for example, 27% of households with children under the age of 18 are headed by grandparents, and grandparents are solely responsible for the children's care in 8% of family households. In rural Tulare County, grandparents head 17% of family households and are solely responsible for childcare in 8%. As more data from the 2000 census are released, a much more complete, county-by-county picture of the prevalence and demographics of California's grandparent caregiver population will emerge.

2. Characteristics of Children Raised by Grandparents

Children in relative headed households frequently have significant health-related problems, particularly those children who came into the grandparents' care having been prenatally exposed to drugs or alcohol, and/or having suffered parental abuse or neglect. High rates of asthma and other respiratory problems, weakened immune systems, poor eating and sleeping patterns, physical disabilities and attention deficit hyperactivity disorder (ADHD) are among the problems experienced, and which in turn may take a toll on the caregiver's physical and mental health. Moreover, one-fifth of children living in grandparent-headed households in California have no health insurance.

3. Impact on Employment and Financial Well-Being

Becoming the primary caregiver for one's grandchildren often means quitting a job, cutting back on hours, or making other job-related sacrifices that may put one's own future economic well being in jeopardy. Retirement plans may be canceled or postponed as grandparents find themselves raising second families, frequently exacerbating already difficult economic circumstances. Some grandparents report spending their life savings, selling their car, or cashing in life insurance to cope financially with the new role.

Those employed grandparents whose work outside the home (e.g., as a graveyard shift aide in a convalescent hospital or a school bus driver) involves many of the same tasks and stressors as their caregiving roles for grandchildren are at higher risk for the negative effects of caregiving.

Grandparents who are caring for their grandchildren informally tend to experience the same or greater levels of hardships as their counterparts in formal foster care, yet have far fewer resources available to them for coping with this situation. California relative caregivers without formal custody, for example, receive just $345 in child only Temporary Assistance to Needy Families (TANF) benefits per month compared to $604 for those with formal foster care designation (Anderson and Righton, 2001). This disparity increases, moreover, with the number of children in the home, since benefits in California, as in most states, increase only incrementally while foster care benefits are paid on a per child basis.

Grandparents who are poor, rural and/or have lower educational attainment also are more likely to be raising grandchildren outside the formal foster care system, and therefore are experiencing lesser access to services and other governmental supports designed to assist formal kinship care providers (Burnette, 1998; Minkler, 1999).

4. Impact on Health and Personal Well-Being

Faced with challenges such as these, grandparents raising grandchildren are at significantly increased risk for depression, functional limitations and financial difficulties. They frequently report chronic health problems, and 56% have limitations in one or more self-care activities. One national study found that 32% of caregiving grandmothers met clinical criteria for depression, compared to 19% of non-caregiving grandmothers (Fuller-Thomson and Minkler, 2000). Grandparents raising grandchildren often report substantial declines in marital satisfaction, as well as decreased socialization with friends and family, and an inability to continue participation in church and senior center activities.

Rural grandparent caregivers have reported particularly high rates of social isolation, and few support groups and other resources have been developed to meet their needs. Grandparents with lower educational levels also have reported the added stress that comes with being unable to help children with their homework and/or to effectively navigate school bureaucracies and other systems of care.

Early research in Los Angeles (Burton and Bengston, 1985), corroborated in Oakland (Minkler and Roe, 1993), also suggested that great-grandparents constitute a particularly vulnerable group of relative caregivers. In such families, responsibility for grandchildren has been "pushed up the generational ladder" from grandparents (many of them still working) to the oldest generation. These great-grandparents often reported resentment at being placed in this situation during a time in life when they expected to be taken care of, and many reported social isolation and the exacerbation of chronic health problems, such as hypertension and arthritis, which they attributed to the caregiving role.

Research among African American grandparent caregivers in Oakland, CA, (Minkler and Roe, 1993) found that grandparents who were simultaneously raising grandchildren and caring for disabled elderly parents exhibited the highest stress levels and depressive symptomatology.

C. Vulnerable Caregivers

Certain individuals are especially vulnerable to the deleterious effects of caregiving, whether for a child or a disabled elderly person. Those who care for someone with problematic behaviors, dementia, or a high level of daily dependency or for multiple care recipients, are at especially high risk for depression and other negative outcomes. Other vulnerable caregivers include those who have health problems of their own, share a home with the care recipient, have conflictual familial relations, experience occupational conflicts or strains, or are socially isolated (Scharlach et al., 2001).

Among respondents to the California Statewide Survey of Caregivers, for example, the 20% of caregivers who experience the highest levels of financial hardship, physical strain, and emotional stress differ from other caregivers in a number of important ways. First, those in the "most stressed" group are more likely to be female, Latino, lower income, and in poorer health. They are more likely to care for someone with mental illness/emotional problems, dementia/memory problems, behavioral problems, or stroke or paralysis. They are more apt to report that they need more help than they are receiving from family, friends, or community organizations. Furthermore, they are more likely to report that the caregiving situation has created family conflict and has been a significant hardship for their families.

Similarly, grandparent caregivers living in poverty, those in rural areas, and those with less than a high school education are some of the sub groups that have been found to be particularly vulnerable, and merit particular attention by service providers and policy makers. In each of these cases, grandparents may have more difficulty accessing needed health and social services, or even knowing about the services and programs for which they are eligible.

II. STRENGTHS AND DEFICIENCIES OF CALIFORNIA'S CAREGIVER SUPPORT SYSTEM

A. Existing Resources

1. State Resources for Family Caregivers

California has a vast array of potential resources for family caregivers. Programs for caregivers are administered by several state departments within the Department of Health and Human Services (DHHS), including the following: the Department of Aging, the Department of Developmental Services, the Department of Health Services, the Department of Mental Health, and the Department of Social Services (Table 3). Each of these state departments channel funding from various sources to a range of public, private, and not-for-profit service-providing organizations (Friss-Feinberg, et al., 2002).

The California Department of Aging (CDA) administers the National Family Caregiver Support Program (Title III, part E, of the Older American's Act of 2000), through a network of 33 Area Agencies on Aging (AAAs), 15 of which are co-located with county agencies. Services provided under the NFCSP include: (1) information about caregiver services; (2) assistance gaining access to services; (3) counseling, education and training to assist caregivers with problem-solving and decision-making; (4) respite services; and (5) supplemental services to complement these four areas.

Other CDA-administered programs that benefit family caregivers include: Information and Assistance, Adult Day Care, Adult Day Health Care (ADHC), Alzheimer's Day Care Resource Centers (ADCRC), Case Management programs including Linkages and Multipurpose Senior Services Program (MSSP), Respite services, Senior Companion program, and the Alzheimer's Federal/State Matching Grant Program.

The Department of Developmental Services provides services and supports for over 155,000 children and adults with developmental disabilities. These services are provided through state-operated developmental centers and contracts with 21 nonprofit agencies called Regional Centers. Many of these adults and children with developmental disabilities are cared for by aging parents or grandparents.

TABLE 3. STATE PROGRAMS SUPPORTING CAREGIVERS[3]

Department/Program	Description	Funding Source	# Served	Annual Expenditures	Year of Expenditures
CA Department of Aging					
Adult Day Care	Therapeutic and social services	OAA	3,093	$5,885,620	FY 2001/02
Adult Day Health Care	Health care and social services	Medi-Cal	9,136	$46,740,000	FY 2001/02
Alzheimer's Day Care Resource Centers	Support groups, counseling, respite	State General Fund	7,397	$3,758,000	FY 2001/02
Case Management		OAA	29,370	$6,657,106	FY 2001/02
Linkages	Case management and service referral	State General Fund	2,451	$2,029,000	FY 2001/02
Multi-Purpose Senior Services Program	Case management and service referral	Medi-Cal	9,000	$28,000,000	FY 2001/02
Respite Services		OAA		$17,752	FY 2001/02
Senior Companion Program	State funds to link volunteer seniors with those in need	State General Fund	1,880	$645,000	FY 2001/02
Alzheimer's Federal State Matching Grant Program	Coalition of service providers develop local support services for people with dementia and their caregiver in ethnically diverse communities	OAA		$500,000	FY 2001/02
National Family Caregiver Support Program	Federal funding allocated to states to provide information, access, counseling and training, respite, and other supplemental services to assist individuals who are caring for older adults or to assist older adults who are caring for children	OAA	9,095	$10,791,861	FY 2001/02

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[3] Data for Respite, CRC, NFCSP, and Kinship Programs are specifically for services for caregivers; for other programs, caregiver specific data is not available. However, caregiver estimates for some programs can be estimated; for example, 70% of IHSS clients receive services from family or other informal care providers.

Department/Program	**Description**	**Funding Source**	**# Served**	**Annual Expenditures**	**Year of Expenditures**
Department of Developmental Services					
Regional Centers	Range of services for persons with developmental disabilities	Various State Funds	4,394	$75,531,315	FY 2001/02
Department of Health Services					
Alzheimer's Disease Program	Diagnoses and treatment, support groups, education, training, & service referral	Various State Funds	1,000	$4,900,000	FY 2001
Department of Mental Health					
Caregiver Resource Centers	Information and referral; education, training, counseling, support groups, legal & financial consultations; in-home family consultations and care planning; respite care options; Internet support	State General Fund	14,201	$10,859,209	FY 2001
Dept of Social Services					
Adult Protective Services	Emergency investigations, services, case management	State (Title XXI)	15,129*	$80,841,000	FY 2001
In-Home Supportive Services	Personal care program for aged, blind, and disabled; domestic services, personal care, respite care	Medi-Cal & State General Fund	153,312	$2,563,805,012	FY 2000
Kinship Support Services	Provides community-based family support services to kinship caregivers and the children placed in their homes	State General Fund	1,995	$2,775,000	FY 2000
Kinship Guardianship Assistance Payment	Provides financial assistance, equal to the basic foster care rate, to relative caregivers who become legal guardian of a child	TANF, State General Fund & County Funds	10,842	$69,900,000	FY 2002/03

*monthly caseload

The Department of Health Services provides services to persons with Alzheimer’s disease and related disorders and their families through the Alzheimer's Disease Program (ADP) and the Alzheimer’s Disease Research Centers (ARCCs). Under the ADP, ten ARCCs are administered through university medical centers throughout California. These Centers are dedicated to improving the quality of life of persons affected with Alzheimer's disease and their families by providing services such as: comprehensive assessment of individuals with memory problems; in-home assessment of functional abilities and safety concerns; family conferences and treatment planning; information and referrals to community health and social services; support groups for caregivers; training and education for professionals and lay audiences; and follow-up services for families. The ARCCs also provide education and support to the families of persons with Alzheimer's disease.

The Department of Mental Health administers 11 regional *Caregiver Resource Centers* (CRCs), which offer a broad range of services primarily to caregivers of adults with adult-onset cognitive impairments, including: information, advice, and referral; assessment of caregiver needs; long-term care planning and consultation; legal and financial consultation; mental health interventions such as counseling, support groups and psycho-educational groups; *Link2Care*, an Internet-based information, support and education program, education and training programs; and a range of respite care services. The CRCs use a consumer-directed care model, offering a flexible array of services to predominantly middle-income families who are ineligible for other public benefits and cannot afford to pay for services out-of-pocket. Services are free or low cost. The CRC system was the first state-mandated program in the country to address the needs of families and friends providing long-term care at home.

Family Caregiver Alliance (FCA) serves as the Statewide Resources Consultant for the CRCs. FCA’s information clearinghouse produces fact sheets on caregiving issues, reports of current statistics and research in the area of caregiving, and a free electronic newsletter providing current news on nationwide policies and programs related to caregiving and long-term care. FCA also administers the *National Center on Caregiving* (NCC), which provides information and technical assistance for caregiver program administrators nationwide, and public policy research for state policymakers, planners, and other stakeholders.

Under the auspice of the California Department of Social Services, In-Home Support Services (IHSS) assists functionally-impaired adults to access and pay for in-home care. In approximately 70% of IHSS cases, family members or friends provide the care, which is paid for through the IHSS program. IHSS also provides limited respite care for family caregivers. Adult Protective Services (APS) provides counseling for caregivers of adults at risk of abuse or neglect. Both IHSS and APS are sometimes administered within the same county department as the AAA.

The Kinship Support Service Program (KSSP) funded by the Department of Social Services is modeled after the Kinship Support Network (KSN) program developed as part of a larger model by the Edgewood Center for Children and Families. KSSP provides community-based family support services to kinship caregivers and the children placed in their homes. In addition, the Kinship Guardianship Assistance Payment program (Kin-GAP) is a voluntary program that provides financial assistance to relative caregivers who become legal guardians of a child. Kin-GAP provides a monthly stipend equal to the basic foster care rate (not including supplemental funds) based on the child's age (Reed and Karpilow, 2002).

Caregivers in California also are eligible for a $500 tax credit, which is available for individuals who provide or pay for care at home for seniors or persons of any age with disabilities. In addition, California's Paid Family Leave Law (S. 1661, 2002), which becomes effective in 2004, will allow employed persons to take up to six weeks a year of paid time off to care for a child or a seriously ill spouse, parent or child.

2. Local Caregiver Resources

To gather information on local resources for family caregivers, caregiver provider inventories from the 2001-2005 Area Plan Title III-E addenda for all 33 California AAAs were reviewed. In addition, a questionnaire was designed and distributed electronically to the 33 AAAs, asking them to provide a complete resource list of caregiver services in their respective planning areas and to identify the major providers of these caregiver services. The questionnaire also asked each AAA to assess the adequacy of current services within each NFCSP service category. Responses were received from 24 (or

73%) of the 33 AAAs, representing approximately 86% of California's population aged 65 and older (Scharlach et al., 2002a).

An Internet search also was conducted, to supplement the information received from the AAA Area Plan inventories and questionnaires and to identify service providers that exist outside of the aging service network. The Internet search also provided information for those AAAs that did not present an inventory as part of their Title III-E addendum or did not complete the questionnaire.

In all, the AAAs identified a total of 304 individual caregiver support providers throughout the state. Of these 304 organizations, 35% provided informational services; 26% provided assistance to caregivers in gaining access to services; 25% provided counseling services, support groups, or caregiver training; 63% offered respite services or facilitated access to respite; and 29% provided or assisted caregivers in obtaining supplementary services, such as transportation, nutrition, or financial assistance.

The types of caregiver support organizations identified by the AAAs included the following: Caregiver Resource Centers (identified by 78% of AAAs); adult day care and day respite programs (67% of AAAs); general community social service programs, such as support groups, senior centers, and faith-based organizations (identified by 61% of AAAs); public agencies, such as "AAA" and "IHSS" (52% of AAAs); medical care providers, such as primary care physicians or health maintenance organizations (24% of AAAs); and allied health care professionals such as home health or hospice care (33% of AAAs); publicly-funded case management programs, such as Linkages and MSSP (33% of AAAs); disease-specific organizations, such as the Alzheimer's Association (27% of AAAs); residential care and overnight respite providers (24% of AAAs); and legal services (18% of AAAs).

3. Service Use

The California Statewide Survey of Caregivers provides information about the types of services caregivers actually use. In all, 70% of caregivers report receiving one or more support services from a community agency or other formal service provider. Analysis reveals that White non-Hispanic caregivers are 1.9 times as likely to use formal services as are Asian Americans and Pacific Islanders, and 1.5 times as likely as Latinos.

African American caregivers are 2.6 times as likely to use formal services as are Asian Americans and Pacific Islanders, and 1.9 times as likely as Latinos.

As Table 4 illustrates, when the specific sources of assistance are examined, it is clear that community organizations and other formal service providers are the primary sources of most types of support. Family members and friends were the primary sources of support with regard to in-home respite, overnight out-of-home respite, and emotional support from peers.

TABLE 4. ASSISTANCE RECEIVED BY CAREGIVERS (TYPES AND SOURCES) DURING THE PREVIOUS YEAR (N = 1643)

SERVICES OR SOURCES OF HELP	% from family and/or friends*	% from agency or other provider*	% from unspecified source*	% receiving the service overall
In home respite	26%	9%	3%	38%
Education or training	4%	24%	3%	31%
Information about community services	4%	22%	4%	30%
Information about legal rights/obligations	6%	17%	3%	26%
Someone to talk to (e.g. support group)	14%	10%	1%	25%
Financial information and advice	4%	13%	3%	20%
Advice/counseling from clergy	2%	7%	10%	19%
Professional counseling	1%	6%	8%	15%
Overnight respite	6%	5%	2%	13%
Day respite	1%	4%	7%	12%
Help getting or using community services	3%	7%	2%	12%
Any other service from another agency or organization	0.4%	4%	7%	11%

* Some care recipients received services from multiple sources

The services most often received from formal service providers include education, general information about services, and legal services. The most frequently utilized formal sources of support are health care providers (especially for education, information, and counseling), followed by AAAs and other public entities (for financial advice and information about services), residential care providers (for in-home and overnight respite), professionals (for legal and financial advice), other agencies and community-based organizations (for information about services), and religious organizations (for pastoral counseling and peer group support).

4. Satisfaction with Services

As shown in Table 5, caregivers generally feel that their needs were met regardless of the service that they used, with satisfaction levels exceeding 90% for most types of services.

TABLE 5. SATISFACTION WITH CAREGIVER SERVICES RECEIVED

SERVICES OR SOURCES OF HELP	Percent reporting needs were met
Advice/counseling from clergy	94%
In home respite	93%
Information about legal rights/obligations	93%
Overnight respite	93%
Education or training	92%
Day respite	92%
Help getting or using community services	92%
Support group	91%
Financial information and advice	89%
Professional counseling	88%
Any other service from another agency or organization	86%
Information about community services	83%

5. Grandparent Kin-Carers

The oldest and most comprehensive program in California for relative caregivers of children is the *Kinship Support Network (KSN)* model developed by the Edgewood Center for Children and Families. The program was the first in the nation to provide comprehensive, private-sector support services to relative caregiver families. Serving 225 families daily and more than 3,500 annually in San Francisco and San Mateo

Counties, the program is designed to fill any gaps in public social services to relative caregivers and their families. One-on-one peer mentoring, parenting education, support groups, case management, health assessments, nutrition counseling, transportation assistance, emergency tangible goods, and family activities are among the services offered.

Edgewood's KSN program has been designated as a model by the State legislature in Assembly Bill 1193, which has charged the program administrators with providing technical assistance, training other kinship support programs around the state and writing a detailed training manual for new providers (Cohon, 2001). AB 1193 mandates the Department of Social Services to oversee the implementation of Edgewood's kinship support model, known as the California *Kinship Support Services Program (KSSP)* in eligible counties. The model has been implemented in 11 counties within California (Cohon, 2001), while six additional counties are currently approaching implementation. Researchers at the Center for Social Services Research, University of California at Berkeley, are currently evaluating the KSSP network.

At the State level, the service network that exists for older adults caring for young family members is smaller than the array of services currently available for caregivers of older adults. In addition to the KSSP network, most support services for family caregivers of children consist of local community social service programs, such as support groups and faith-based organizations, often funded privately through community or faith-based organizations. Similarly, the model Grandparents as Parents (GAP) Inc. in California consists of small autonomous groups established and led by health or social service providers, or by grandparent caregivers themselves.

6. Summary of Caregiver Service Utilization

According to information provided by AAAs and collected via the internet, the support services most likely to be available for caregivers include caregiver information, counseling and other services provided through the Caregiver Resource Centers, daytime respite offered through the various Adult Day Programs, and general community social service programs such as support groups, senior centers, and faith-based organizations.

According to caregivers themselves, the types of support they are most likely to actually use include in-home respite, education and training, information about community services, legal assistance, and group support. Of these, formal providers were the primary source for education and training, information about community services, and legal assistance. Caregivers are more likely to rely on informal sources for in-home respite and emotional support.

The next sections of this report will discuss caregivers' unmet needs and make recommendations for making caregivers' stated needs and existing resources more compatible with one another.

B. Unmet Needs

1. Caregiver Needs Identified by AAAs

In their Title IIIE Area Plan Addenda, AAAs identified existing service needs of local caregivers. While some AAAs cited as few as two needs, others identified more than 40 needs experienced by caregivers in their respective planning areas (Scharlach et al., 2002b).

The needs identified most often by the AAA respondents included the following: respite care (by 31 of 33 AAAs), information and assistance (25 AAAs), caregiver training (20 AAAs), case management (14 AAAs), counseling (13 AAAs), outreach (12 AAAs), and transportation (11 AAAs).

The survey administered to AAAs asked them also to identify gaps and inadequacies in their existing caregiver service networks. Overall, the most common gaps identified among general caregiver services consisted of the following: culturally and linguistically appropriate services, transportation, respite, financial assistance, and care in rural areas.

a) Culturally and linguistically appropriate services. The unavailability of multilingual and culturally appropriate services for caregivers of older adults was by far the most frequently identified gap in the current service network. Failure of existing services to meet caregivers' cultural and linguistic needs was identified for each of the five NFCSP existing services by a majority of AAAs. Three-fourths of AAAs cited the lack of multilingual and culturally appropriate information, while 67% indicated that access services were not multilingual and culturally appropriate, and 50% considered translation services to be lacking. Languages in which services do not seem adequate include Russian, Farsi, Portuguese, Spanish, Lao, Mien, Cambodian, Korean, Chinese, and Hmong. The challenge of developing trust among various ethnic communities also was mentioned as a barrier to providing adequate support throughout diverse communities.

b) Transportation. Transportation was identified as a service gap by 75% of AAAs. In both rural and urban communities, transportation is a challenge for older adults as both driving and taking public transportation become increasingly difficult. The lack of transportation available to caregivers serves as a barrier to accessing services both for themselves as well as for those for whom they are providing care

c) Respite care. The type of respite most often identified as a major service gap for caregivers of older adults was emergency, unplanned respite, identified by 79% of AAAs. Specific types of respite services that were most often identified as inadequate were overnight and weekend respite, especially in the care recipient's home.

d) Financial assistance. Financial assistance to assist caregivers in gaining access to services was considered inadequate by 63% of AAAs. One-time emergency cash assistance, different from on-going subsidization of caregiver services, was deemed inadequate by approximately half of the AAA respondents.

e) Care in rural areas. The majority (54%) of AAAs deemed community services in rural areas inadequate, particularly with regard to the availability of in-home workers. Other gaps identified by AAAs include outreach to increase caregivers' access to services (38%), case management/comprehensive assessment (33%), and coordination of services (29%).

2. Barriers to Service Use Experienced by Caregivers

The California Statewide Survey of Caregivers (Scharlach et al., 2003) included questions designed to tap caregivers' reasons for not using services they would otherwise find useful. As shown in Table 6, 19% to 67% of caregivers who did not use particular types of support would have considered those supports helpful if they could have used them. The services considered most helpful were information about community services, legal assistance, financial advice, help accessing services, and education or training.

TABLE 6. SERVICES CONSIDERED POTENTIALLY HELPFUL TO CAREGIVERS
(of those who did not receive service)

SERVICES OR SOURCES OF HELP	Service would have been helpful	Do not know where to get service
Information about community services	67%	64%
Information about legal rights/obligations	64%	74%
Financial information and advice	57%	74%
Help getting or using community services	53%	54%
Education or training	49%	66%
Support group	42%	58%
Help with care receiver in home	33%	56%
Professional counseling	32%	58%
Day respite	30%	48%
Advice/counseling from clergy	27%	26%
Overnight respite	19%	62%

Lack of knowledge was the major reason for not using services. Three-fourths of caregivers needing financial or legal assistance did not know where to get it. Two-thirds of those desiring education, training or information about services did not know where to get these services.

Aside from lack of knowledge of a particular service, other reasons often given for not using desired services were the cost of services, the reluctance of the care receiver to desire the help, the sheer lack of availability, poor quality of service, and lack of availability at the times it is needed, as shown in Table 7. However, 70% of caregivers also said that they already have all the help they need.

TABLE 7. REASONS GIVEN FOR NOT RECEIVING MORE OUTSIDE HELP
(excludes those who say they already have all the help they need)

	% listing this reason
Services cost too much	17
Care receiver doesn't want the help	13
Services are not available	12
Service quality is poor	11
Not available at times needed	10
There is no one to stay with care receiver while help is sought	8
No time to get help for yourself (the caregiver)	8
Services not offered by people who are like you (caregiver)	8
Transportation is not available	7
Service providers don't speak language	5

3. Needs of Grandparent Kin-Carers

Grandparents have a variety of service needs, which should be addressed if they are to be better positioned to cope effectively with the demands of caring for a young child. These include social support, financial assistance, health insurance, legal assistance, and housing. However, grandparents frequently delay or fail to seek formal assistance for their own needs, despite their increased risk of physical and mental health problems (Burnette, 1998; Minkler and Roe, 1993; Shore and Hayslip, 2000).

a) Social support. Support from friends, family, and community can help to ameliorate some of the extra demands faced by older adults who find themselves responsible for a child's care. However, grandparent kin-carers often face social isolation, particularly when their caregiving role has been necessitated by parental AIDS or drug addiction, resulting in stigma and shame in some religious and cultural communities (Joslin, 2002; Minkler, 1999).

b) Health care coverage. Accessing needed health services for the grandchildren in their care can be impeded by lack of insurance coverage. One in five children living in grandparent-headed households in California lacks health insurance. Many insurance companies refuse to allow grandparents to include grandchildren as dependents on their insurance policies unless the children are in legal custody of the policyholder.

c) Financial assistance. Becoming the primary caregiver for one's grandchildren often exacerbates financial problems. In one study of African American grandmother caregivers, most of whom lived in low-income neighborhoods in Oakland, over 50% described themselves as "doing poorly" financially. None said they were "doing well" (Minkler & Roe, 1993). The fact that 60% of all kinship care families nationally are income eligible for and receive Food Stamps (Ehrle et al., 2001) is a further indication of the substantial financial need experienced by this population.

d) Legal issues. Legal assistance is a major need for many grandparents, as they attempt to define the legal status and obligations of their quasi-parental role. Formalizing legal authority is essential for accessing needed services and supports for the children in their care; however, the legal proceedings involved can be costly, time consuming, and emotionally wrenching.

e) Housing. Access to adequate and affordable housing is a major concern for many older adults who are raising grandchildren. Low-income caregivers in particular may be severely limited in their ability to purchase adequate housing, and state level public housing authorities lack policies that address the special needs of such families. Grandparents in senior housing can be evicted for taking in grandchildren, while in other types of pubic housing, legal guardianship papers may be required to prevent eviction. Even grandparents who are allowed to have their grandchildren live with them often report that space is an issue, and particularly having an adequate number of bedrooms. Finally, recent data from the 2000 Census suggests that grandparent caregivers who are renters face special difficulties; for the quarter of a million grandparent caregiver renters living below the poverty line, for example, over 60% spend at least 30% of their household income on rent, and three of ten live in over-crowded conditions (Fuller-Thomson and Minkler, in press).

C. Service Implications

In this section we discuss major service implications of our findings, including specific programs to meet caregivers' unmet needs, interventions for vulnerable caregivers and key service providers. These recommendations will be discussed further in Section IV, as building blocks towards a comprehensive caregiver support system.

1. Specific Programs to Meet Unmet Needs of Family Caregivers

Unmet needs identified most frequently by caregivers included information about where to find and how to access services, caregiver training, and financial and legal assistance. Other needs identified by AAAs but less frequently by caregivers themselves included respite care, transportation, and culturally and linguistically appropriate services.

a) Information about community services. Lack of knowledge about community supports has been identified by AAAs and caregivers alike as the primary barrier preventing caregivers from obtaining the assistance they need. Even when services are available, many caregivers remain unaware of them. Moreover, current and future caregivers all benefit from information regarding health conditions and their implications, available services and how to access them, and other information essential for effective care planning. Local and statewide efforts should be taken to expand existing information and assistance programs to reach current caregivers, and to initiate public education programs designed to enhance general awareness of caregiving issues.

b) Assistance accessing services. Information about available services does not necessarily translate into caregiver service utilization. Other barriers to service use include availability, accessibility, appropriateness, acceptability, and affordability. For example, there appear to be wide variations in the range of caregiver supports offered in each PSA, and one of the primary reasons caregivers give for not using services is that the services simply are not available in their community.

Those services that are available must be accessible. Transportation is one of the major barriers identified by AAAs. Services must be offered in places and at times that can reasonably accessed by caregivers, including those who have limited mobility, who do not drive, or who are not available during normal working hours. Services also must be culturally appropriate, employing bilingual and bicultural personnel whenever possible. Efforts should especially be directed at overcoming cultural and linguistic barriers faced by Latinos, Asian Americans, and Pacific Islanders, who are significantly less likely to utilize services than are African Americans and Non-Hispanic Whites.

Fourth, services will not be used unless they are acceptable, and care recipient resistance is identified as a primary reason for not using caregiver support services. Counseling, whether conducted in an individual, group, or family format, can help to mollify conflicts between the caregiver and care recipient, resolve pre-existing personal problems which complicate caregiving, and/or improve family functioning.

Finally, services must be affordable to caregivers. Caregiver consideration of the affordability of services not only includes financial costs, but also costs in terms of time, effort, potential loss of confidentiality, and potential family conflict. Services with narrow selection criteria or high costs/co-pays significantly undermine the availability and accessibility of formal services for many caregivers. Minimizing such costs increases the likelihood of caregiver service utilization.

c) Education and training. Caregivers and AAAs identify education and training as a major unmet need. These might include training in specific caregiving tasks, education about disease processes, or problem solving and coping techniques. Recent research by Gallagher-Thomson and colleagues suggests that culturally tailored skills programs can be more effective with Latina and Caucasian women than a traditional support group in reducing caregiver depression, increasing positive coping, and fostering aspects of social support.

d) Financial and legal assistance. Caregivers report needing information about sources of financial assistance and advice to help them plan for providing care, as well as financial assistance to help pay for caregiver support services. They also indicate the need for information about their legal rights and obligations as caregivers.

2. Specific Programs to Meet Unmet Needs of Grandparent Caregivers

Each of the five problem areas described in Section I (inadequate social support, health care coverage, financial assistance, legal assistance, and housing) lends itself to the development or replication of programs which can help address unmet needs. Described below are the specific needs such programs might address, what they might look like, and examples of particular programs which could profitably be replicated on a larger scale to help meet this growing challenge.

a) Social support. Even grandparent caregivers with strong family networks have been shown to benefit from support groups comprised of other grandparents in like situations. Although most such groups operate on a volunteer basis and are in fact started by grandparents themselves, many are short lived in part because of the lack of even minimal outside support to pay for supplies, childcare and other basic needs. New grandparent caregivers further may not be acquainted with such groups or know how to go about accessing them. Although AARP's Grandparent Information Center is an excellent resource, providing grandparents and providers alike with information on support groups and other programs in their geographic areas, their small staff, and the difficulty of keeping tabs on the literally hundreds of support groups around the U.S., suggest the importance of having more localized information and referral services available. AAA's vary in their ability to track and provide such information, even to those grandparents who know to contact them. Far greater outreach and support for information and referral on support groups for grandparents, as well as information on how to establish and help sustain such groups, is needed on the local level. Small grant programs, similar to the $2000 mini grants offered on the national level through the Brookdale Foundation's RAPP (Relatives as Parents Program), would be a helpful means of facilitating new support group development and operation.

For many grandparent caregivers, social isolation may also result from the inability to find time for one's self which could be used to visit friends, see other grandchildren, or participate in valued church or volunteer activities. To date, very few respite programs have been developed for grandparent caregivers, and the creation, support and publicizing of both center-based respite programs and limited in-home respite would also help fill a critical unmet need in this area. The Catholic Charities Grandparent Resource Program in San Jose, CA, offers a useful model, contracting with local childcare centers to provide very low cost respite care to grandparents for up to 5 hours per week. On the state level, the Oklahoma Respite Resource Network offers a voucher respite program through its AAAs, which are reimbursed from the Department of Human Services when eligible grandparents obtain respite care at local contracting child care centers. Oklahoma's NFCSP funds are being used in part to expand this program for older (60+) grandparents with other funds used to serve younger grandparents in need.

b) Health care coverage. The significantly lower access to health insurance among children in the care of grandparents suggests the need for targeting outreach through the CHIP (Children's Health Insurance Program) and similar vehicles to intergenerational households headed by grandparents. In addition, the tendency of many caregiving grandparents to ignore their own health symptoms and needs while focusing on the grandchildren, suggests the utility of "one stop shopping centers" at which grandparents can receive care for themselves as well as their grandchildren. Finally, assistance in navigating the complex health care system, provided through programs such as the Edgewood Center's Kinship Support Network of Northern California, can be of substantial assistance in this regard, and increased resources for such programs would enable them to extend their reach.

c) Financial assistance. A telling finding of the National Survey of America's Families was that 73% of low income children in the foster care system receive government benefits, compared to just 25% of those in kinship families with no contact with child welfare agencies. From the perspective of financial assistance, then, the most critical need is for locating the large number of low income grandparent-headed households outside the system and finding creative ways to assist them in accessing the benefits to which they may be entitled. Helping grandparents outside the system access cash and other assistance through CalWorks for the children in their care is a critical step in this regard. For grandparents in the foster care system who have had their grandchildren for a year or more, help in accessing Kinship Guardian Assistance (Kin-GAP) payments, which are equal to the state's basic foster care rate, also should be made a priority.

d) Legal assistance. As indicated above, grandparents raising grandchildren are likely to receive far more generous financial and other assistance if they are in the formal foster care system. Yet getting into the system can seem daunting, particularly for low income grandparents with limited education. Ohio's Department on Aging offers a helpful model in this regard, funding a "kinship care navigator" to help grandparents negotiate the legal system and access needed benefits. That state's creation of a toll free hot line for kinship caregivers represents another creative approach that state units on aging may wish to emulate. The offering of free guardianship clinics by Grandparents

Parenting Again and co-sponsored by the local Superior Count in Sonoma County, CA; day long legal seminars for grandparents raising grandchildren, modeled on one offered by the Decatur Bar Association in Illinois; and the provision of pro bono legal services at special Grandparents' Day events in Oakland, CA, and through comprehensive service organizations also can be of great help to such caregivers. Finally, the publication and wide distribution of resource guides for grandparent caregivers, which include state-specific legal information in clear, accessible language can be of considerable assistance. The Resource Manual for Relative Caregivers developed by San Francisco's Legal Assistance to Prisoners with Children provides a good model in this regard, with a Q & A format especially helpful in relation to the extensive legal information provided.

e) Housing. As noted above, grandparents who take in grandchildren may face eviction from senior housing; discrimination in attempts to access other public housing if they are not formal kinship care providers; overcrowding; and other difficulties. Grandparent caregivers who are renters are also particularly vulnerable to both paying a high proportion of their incomes on shelter and living in overcrowded homes (Fuller-Thompson and Minkler, in press). Several helpful avenues to addressing these unmet needs have been suggested by Generations United, including the provision of training and education, through both HUD and the Fair Housing Initiatives Program, for front line workers who often appear to be misinterpreting policies that affect grandparent headed families. Such training would clarify, for example, that grandparents are not required to have legal custody of children to qualify as "family" for certain government-assisted housing programs.

Treating grandparent and other relative-headed households as "families" rather than "interim families" for purposes of the Family Reunification Act, also is recommended so that children cease being prevented from entering the foster care system due to space limitations of a family member's housing (Generations United, 2001).

Finally, intergenerational housing specifically designed to meet the needs of such households should be developed. An important prototype may be found in Boston's GrandFamilies House. A 26 unit complex of two, three, and four bedroom apartments built expressly to accommodate the needs of relative caregivers and their families, GrandFamilies House provides physical accommodations to aid both toddlers and seniors, on-site programs, and a task force to promote advocacy on behalf of grandparent headed households. Created by two local non-profits, GrandFamilies House is supported through both Section 8 vouchers and federal "HOME" housing program funds (Kauffman and Goldberg-Glen, 2000). Replications of GrandFamilies House are getting underway in more than a dozen cities around the U.S., and California, with the largest number of such caregivers in the nation, may well wish to adapt this model in some of its most heavily impacted regions.

In sum, while the needs remain substantial and diverse, there are many promising models for helping to address the unmet needs of the state's growing number of grandparents raising grandchildren.

3. Proven Interventions for Vulnerable Caregivers

Certain individuals are especially vulnerable to the deleterious effects of caregiving, including high levels of physical strain, depression, family distress, work-family conflict, or other negative outcomes. Vulnerable caregivers include those who care for someone with problematic behaviors, dementia, or a high level of daily dependency, or who are poor, socially isolated, or have health problems of their own.

Programs which offer a combination of counseling, support, and education have been found to be especially effective in helping vulnerable caregivers. Individual counseling can be especially useful for narrowly defined problems, particularly if it includes problem-solving and behavior-management skills training. Family counseling can reduce family conflict and improve communication. Support groups can reduce isolation, while case management can help caregivers develop a care plan and access needed services. In-home and day respite are most effective if they are offered relatively early in the caregiving process and on an ongoing basis. Grandparents especially may benefit from access to financial assistance.

4. Service Providers

The service providers most likely to be available for caregivers include caregiver information and counseling together with in-home assessment and family consultation offered through the Caregiver Resource Centers and the Kinship Support Services Program, daytime respite offered through the various Adult Day Programs and child care centers, and general community social service programs such as support groups, senior centers, and faith-based organizations. Caregivers, on the other hand, are most likely to turn to health care providers (especially for education, information, and counseling), followed by AAAs and other public entities (for financial advice and information about services), residential care providers (for in-home and overnight respite), professionals (for legal and financial advice), other agencies and community-based organizations (for information about services), and religious organizations (for pastoral counseling and peer group support). This suggests that AAAs take active steps to include health care organizations, residential care providers, legal and financial professionals, and other caregiver resources in their efforts to plan and coordinate local supports for caregivers.

III. INFORMATION SYSTEMS

Information about caregivers and their needs is critical to the success of state and local planning efforts. Ideally, an integrated CDA-AAA information system would consist of three components: (1) Planning and Service Area (PSA)-level information regarding the characteristics and needs of caregivers in each community, to provide an accurate profile of caregivers and care receivers regionally and statewide for planning purposes; (2) a client-specific data system for identifying the needs of service users and tracking service utilization; and (3) a system for assessing the impact of FCSP services.

A. Local Needs Assessment Activities

Needs assessment is an essential part of the community planning process, assisting AAAs to allocate limited resources in the most effective and efficient manner. Information about caregivers and their needs, examined in the context of existing services, enables AAAs to identify service gaps and priority areas for change. Information is required regarding the needs of all caregivers, including those who don't utilize existing services, in order to assure that resources are targeted where they are most needed, that services are provided in an effective and equitable manner, and that caregivers receive the support they need.

Our review of 2001 Title III-E Area Plan Addenda indicates that AAAs utilize a variety of strategies to gather data regarding the needs of caregivers in their local PSAs. As shown in Table 8**,** the most common method for assessing local caregiver needs is by inference from local or regional population surveys, such as a community survey of older persons conducted for the general four-year Area Plan, which typically contain limited information about caregivers. Some AAAs also reviewed other local survey data about the 60+ population, including city, county, employee, consumer satisfaction, and health insurance surveys.

Although caregiver-specific surveys have the potential to provide the most accurate and useful information about caregivers in the PSA, only three AAAs (9%) reported collecting and analyzing data from a sample survey that was caregiver-specific. Four AAAs (12%) used grandparent-specific PSA survey data to describe the population of those caring for kin/grandchildren, although this typically was limited to the percentage of older adults surveyed who were caring for children.

TABLE 8. NEEDS ASSESSMENT METHODOLOGY BY DATA SOURCE

NEEDS ASSESSMENT METHODOLOGY BY DATA SOURCE	Total # of AAAs (N = 33)	% of total
1. ***Descriptions of the Caregiver Population***		
a. Regional, state, or national survey data	16	48%
b. PSA survey data, general population	20	61%
c. PSA survey data, caregiver specific	3	9%
d. PSA survey data, grandparent/kinship specific	4	12%
2. ***Information about Service Users***		
a. Service providers	5	15%
b. Service users	11	33%
3. ***Focus Groups***		
a. General senior population	7	21%
b. Caregiver specific	2	6%
4. ***Public Meetings***		
a. General senior population	11	33%
b. Caregiver specific	10	30%
5. ***Community representatives/ Key informants***		
a. General senior population	7	21%
b. Caregiver specific	4	12%

Some AAAs gathered information about caregivers and their needs from service providers, either through surveys, focus groups, or other meetings. One third of AAAs also used information gathered directly from service users, most often by reviewing existing Information and Assistance (I&A) records regarding inquiries pertaining to caregiving issues. One AAA reported gathering information from recipients of kinship services through a survey of service recipients.

Some AAAs were able to obtain information about caregivers from focus groups with older adults and other key informants, although only one AAA reported conducting a focus group composed of caregivers themselves. Other information sources included public hearings, community forums, and various meetings of advisory councils, advocacy groups, and other ad hoc committees. Many of these meetings were structured as informational sessions, designed to inform the community about the National Family Caregiver Support Program while also gathering information about caregiver needs from community members and other attendees. Our review of Area Plan Addenda did not identify any public hearings or community forums held specifically for grandparent or kinship caregivers.

B. Steps in the Caregiver Needs Assessment Process

The six tasks identified in Table 9 are essential to the caregiver needs assessment and community planning process. These tasks are consistent with both the minimum requirements put forth by California Code of Regulations §7300, and the guidelines provided by the California Department of Aging Program Memo (PM) 01-10.

1. <u>Describe the Current Population Of Caregivers</u>

A first step in the caregiver needs assessment process is development of a profile of the basic demographic and social characteristics of all caregivers in a PSA, including those who do not currently utilize Title III-E services. This profile of caregiver and care receivers information can best be obtained through a household survey of a representative sample of caregivers, preferably administered every four years, as part of the normal AAA planning cycle. Because of the expense and expertise required to design and implement a representative household survey, it may be advisable to conduct the survey on a regional or statewide basis. This component of the system would be modeled on the recently-completed California Statewide Survey of Caregivers (Scharlach et al., 2003).

TABLE 9. STEPS IN THE CAREGIVER NEEDS ASSESSMENT PROCESS

Steps in the Caregiver Needs Assessment Process

1. Describe the current population of caregivers
   Action: Compile a descriptive and demographic profile of caregivers.
2. Determine existing and unmet needs of caregivers
   Action: Solicit input from professionals, consumers, and advocates.
3. Inventory existing caregiver resources and services
   Action: Identify programs and services already serving caregivers.
4. Identify service gaps, including existing barriers to equitable access to caregiver resources and services
   Action: Assess gaps and analyze barriers.
5. Prioritize the identified service needs of caregivers
   Action: Synthesize information gathered; weight and rank needs.
6. Design a plan for the delivery of caregiver services that reduces identified barriers to access, supplements existing services, and creates new services where none exist, in the most effective and efficient manner possible
   Action: Implement a decision-making process that results in a plan of action.

2. Describe the Current Population Of Caregivers

A first step in the caregiver needs assessment process is development of a profile of the basic demographic and social characteristics of all caregivers in a PSA, including those who do not currently utilize Title III-E services. This profile of caregiver and care receivers information can best be obtained through a household survey of a representative sample of caregivers, preferably administered every four years, as part of the normal AAA planning cycle. Because of the expense and expertise required to design and implement a representative household survey, it may be advisable to conduct the survey on a regional or statewide basis. This component of the system would be modeled on the recently-completed California Statewide Survey of Caregivers (Scharlach et al., 2003).

One-time-only Title III-E funds might be utilized to help implement caregiver-specific surveys where they have not previously been conducted.

Caregiver-screening items also should be included in existing statewide surveys, such as the California Health Interview Survey (CHIS), or as a supplement to local or regional senior population surveys. In addition to asking survey respondents about their own caregiving activities, those who have disabilities can be asked about any care they receive, as well as basic information about their primary informal caregiver residing in California. The sample population, however, would need to be expanded to include adults 18-59 in order to obtain information from non-elderly caregivers.

For grandparent caregivers, the Census 2000 Supplementary Survey (also known as the American Community Survey) added, for the first time, three questions that enabled a much more direct look at the grandparent caregiver population. These questions asked whether grandparents had any of their own grandchildren under age 18 living with them; whether they were responsible for meeting the basic needs of any of these grandchildren; and if yes, how long they had been responsible (with choices ranging from less than 6 months or less to 5+ years). Combined with other unique additions to the 2000 Census (e.g., the collection of data on 63 different racial groups), these new questions have greatly enhanced our ability to study this population. However, both the ACS and such other relevant data sets as the National Survey of Families and Households (NSFH) fail to ask more detailed questions which would greatly increase our ability to study and formulate programs and policies to assist intergenerational households headed by grandparents. Key among these is the need for questions that would help determine:

- whether the grandparent respondent had formal or informal custody of the grandchild(ren) in his or her care
- whether and to what extent the child(ren)'s parents had contact with their offspring, including provision of help in child-rearing
- whether other members of the grandparent's family (e.g., another adult child or relative) played a secondary caregiver role

- whether the grandparent, if employed when caregiving began, had left work, cut back hours, or in other ways made substantial changes in his or her work life to accommodate caregiving responsibilities.
- For TANF eligible grandparents, whether and in what ways the grandparent was affected by TANF work requirements or time limits
- Whether the grandparent's health insurance covers the grandchildren in his or her care and whether the children have access to other health insurance (e.g., through Medicaid or the CHIP program).

2. Determine Existing and Unmet Needs of Caregivers

Identification of caregivers' unmet needs is essential for determining the types of services and supports that are needed. The types of information that are most useful for service planning include the following:

a) Intake data. Basic information regarding the needs and well-being of caregivers could be collected as a standard component of intake data when caregivers contact AAAs and service providers for information and/or assistance, or when disabled individuals enter the long-term care system. Similarly, the presence and service needs of elderly primary care providers could be collected as a standard component of child/family assessments throughout the child welfare system. One advantage of identifying caregivers through the care recipient is that information could be collected regarding the needs of caregivers who might never attempt to access services for themselves.

b) In-depth interviews. Information that is representative of the needs of all local caregivers can be collected through in-depth interviews with a randomly-selected sample of caregivers. For example, caregivers identified through statewide, regional, or local population surveys could be contacted for more detailed information about their needs and those of their care recipients. However, this is an expensive approach, and requires that population-based surveys (e.g., CHIS, local senior surveys) collect information regarding the identity and contact information of caregivers identified as part of the survey process.

3. Inventory Existing Caregiver Resources And Services

Caregiver needs must be considered in the context of existing community resources, so that service gaps can be identified. Community resources include services currently being provided under Title III-E, as well as those provided through other public programs (e.g., community-based long-term care case management programs, in-home supportive services, social services), disease-specific organizations, other community-based organizations, health care providers, religious and cultural organizations, etc. Beyond the mere existence of services, the availability, appropriateness, accessibility, and adequacy of existing services also should be considered. Section II of this report described a process for identifying and assessing community resources to support caregivers.

4. Identify Service Gaps, Including Existing Barriers To Equitable Access To Caregiver Resources And Services

Existing community resources should be evaluated in light of identified caregiver needs in order to identify service gaps as well as factors that may contribute to underutilization of needed services. Issues of access should be examined, including barriers that may be attributable to socioeconomic, geographic, linguistic, or cultural factors.

a) Key informants. Community representatives and other key informants are an excellent source of information about barriers to services. Individuals representing the interests of various community groups and constituencies could be polled regarding problems experienced by caregivers in particular communities of interest, barriers to service use, the availability of natural support structures, etc.

b) Focus groups. Focus groups also provide an excellent mechanism for gathering information about caregivers' experiences in obtaining assistance and support. Issues to be addressed might include: what led caregivers to seek outside assistance at the particular time; how they knew where to turn; problems obtaining services; and services used and where provided. Also, the adequacy of service options, including ease of access, range of services available, affordability, linguistic and cultural appropriateness, availability at times when needed; whether the amount and type of service was sufficient, including responsiveness to the individual needs of caregivers, care recipients, and other family members; mechanisms for expressing complaints or concerns; and recommendations for improvement. Focus groups also can provide caregivers an opportunity to share experiences regarding strategies and natural supports that help to alleviate challenging aspects of caregiving, as well as strategies for enhancing positive aspects of providing care.

5. Prioritize the Identified Service Needs Of Caregivers

The needs assessment process is apt to produce a lengthy list of caregiver needs and related service gaps and barriers, only a small number of which can be addressed at any one time. Caregivers' identified service needs therefore must be examined in terms of their priority, so that attention can be given to those which are considered to be most pressing or important.

a) Stakeholder meetings. Priorities can be determined through meetings of key stakeholders, including advocates, service providers, community leaders, disease-specific organizations, government agencies, caregivers, and sometimes care recipients. Nominal group processes, such as Delphi, can be particularly effective mechanisms for achieving consensus regarding a small number of priority issues when working with such a potentially disparate set of constituents.

b) Community meetings. Public hearings and other types of community meetings also can be an effective mechanism for obtaining input from large numbers of community members. Although it may be difficult for consensus to emerge from such gatherings, the ideas presented can provide planners and decision-makers with information about the community's priorities and desires. Moreover, community meetings help to inform large numbers of individuals regarding the issues emerging from the needs assessment process, thereby helping to foster caregiver support activities within existing natural communities of interest and legitimize the expenditure of community resources to assist caregivers.

6. Design a Plan for the Delivery of Caregiver Services

A plan for the delivery of caregiver services should reduce identified barriers to access, supplement existing services, and create new services where none exist, in the most effective and efficient manner possible. Service plans should reflect those services or related activities that are likely to be effective in responding to priority caregiver needs. This requires identification of available options for meeting prioritized needs and consideration of their potential effectiveness and cost.

Information regarding the effectiveness and cost of potential service options can be obtained through a review of existing sources of information regarding caregiver program models and their effectiveness. Potentially useful information sources include, among others: CASAS' report on Caregiver Support Interventions, Family Caregiver Alliance's National Center on Caregiving electronic Caregivng Policy Digest, NASUA's NFCSP Service Package Briefs, and National Health Council's Family Caregiving Agenda for Action.

C. Service Users

Meeting the needs of caregivers in the local community requires an understanding of who uses existing services, the types of services they use, and the effectiveness of those services. To accomplish this, client-specific descriptive demographic information about current service users is required. At a minimum, this information should be gathered on caregivers who are accessing FCSP-funded services. However, basic identifying information about caregivers also could be collected when care recipients enter the long-term care system. Similarly, the presence of elderly primary care providers and their service needs could be collected as a standard component of child/family assessments throughout the child welfare system.

It is likely that much of the requisite data already is being collected by AAAs and/or contractors as part of existing client intake processes. We propose that these data collection fields be standardized, and that they include caregiver and care recipient information. Ideally, the data set would be a component of a comprehensive statewide long-term care data system. At a minimum, it would have fields that are at least partially congruent with those included in the caregiver profile survey, in order to facilitate the comparison of program clients with the representative sample of caregivers in the PSA and identify characteristics of underserved client populations both at the PSA and State levels.

1. Recommended Data Elements

A minimum set of client-specific demographic information that could be collected on service users might include the following data elements, based on the recommendations suggested by Henry Brady, Frank Neuhauser, and Jason Seligman (2003) in their report under SB-910:

- Name
- Social Security Number
- Zip Code of residence
- Race/ethnicity
- Date of birth
- Gender
- Living situation
- Annual household income
- Education
- Marital status
- Language spoken at home
- Care needs of care recipient
- Care recipient's current sources of assistance

A more comprehensive data set of client characteristics might also include the following descriptors:

- Prior utilization of FCSP services
- Prior utilization of other formal services
- Support received from religious, social, and cultural organizations
- Support received from natural helping network
- Adequacy of previous services and support received
- Barriers to service use
- Unmet needs

For planning and service delivery purposes, consideration might also be given to collecting information regarding the presence of specific risk factors, such as the following:

- Acute or chronic health problems
- Mental health problems, whether associated with providing care or preexisting
- Problematic health behaviors, including excessive use of alcohol or controlled substances
- Social isolation
- Conflictual relationships with the care recipient or other family members
- Conflict with other major roles (e.g., work, parenting, marital)
- Other indicators of physical, financial, social or emotional distress
- Care recipients who have problematic behaviors, especially those associated with dementing conditions (e.g., sleep disturbance, unsafe behaviors requiring constant supervision, uncooperativeness)

2. User Information in NAPIS/APR

a) Annual profile report (APR) (CDA 273). The APR requests annual information regarding the number of caregivers who received registered services, including their age distribution, race/ethnicity, marital status, employment, relationship to the person receiving care, whether there are multiple caregivers, poverty level, living in a rural area, and living arrangement. Data on care receivers include the total number served, their age distribution, race/ethnicity, relationship (if under age 18), poverty level, whether living in a rural area, living arrangement, and whether the care receiver is at risk.

The primary strengths of the APR are that it is easy to use, only requires annual submission, and provides CDA with aggregate information on the characteristics of both caregivers and care receivers served by the FCSP. Although collected manually at present, it can easily be adapted to electronic reporting.

3. User Information in Other Data Systems

There are a number of other data systems which either have the current capability or can be adapted to accommodate data regarding caregiver needs. To the extent that these systems could link information about caregivers as well as care recipients, they could contribute to an integrated assessment system that would enable relational tracking of service utilization and outcome data.

a) CRCs. Caregiver Resource Centers currently collect information about family caregivers who contact the CRCs for help beyond basic information, using a uniform, comprehensive assessment instrument. In addition to the care receiver's levels of functioning, informal and formal support, and health, caregiver specific areas assessed include the following: general demographics, assessment of caregiver strain (adapted Zarit interview), and information needs.

b) SF-GetCare. The SF-GetCare project has created a web-based Consumer Assessment, Referral, and Enrollment (CARE) tool, for recording, tracking managing and reporting information on Department of Aging and Adult Services (DAAS) consumers and the services they receive. The CARE tool standardizes assessments for all DAAS programs and automates the referral process. The Online Multi-Agency Case Management System for Coordinated Care combines information from all major CLTC programs and develops a web-based system to allow service programs serving the same individual to coordinate care by sharing assessments, care plans and progress notes, with the consent of the consumer.

c) Q Continuum Management System. The Q Continuum Management System offers an online approach for collecting client data across various health and human services agencies. Data elements collected by the Q system include the following: Agency related data (e.g., address, phone number contacts, hours of operation; services available from the agency; guidebook); Client Demographic Data; Client intake/assessment data, Clinical (Health condition, Medications, Allergies, DME, Nutritional risk, Cognitive, ADLs/IADLS, Functional independence, Insurance) and Social (Income, Expenses, Environmental, Family members, Location data).

d) KSSP. The KSSP sites, created under AB 1193 to support grandparent/kin caregivers, use a database to track client specific information, including most of the recommended client-specific service users data elements listed above. Other measurement requirements that may be specific to different counties can be added into the core database structure.

D. Service Utilization

A comprehensive service tracking system provides a mechanism for assessing the service utilization patterns of individual clients, and then utilizing individual-level information to understand aggregate service use patterns. A common data set providing unduplicated client counts can enable AAAs to discern who uses specific types of services; service intensity (e.g., the number of service units utilized by a client); and the total number of unduplicated clients served by the FCSP. Such data would allow CDA to respond in greater detail to administrative and interest group requests for information about clients served under the FCSP, and provide information to better understand client characteristics associated with FCSP service use patterns.

The greatest obstacle to obtaining accurate data is devising a system that encourages proper data collection and reporting. The processes for collecting the data, inputting it into a computer system, devising checking systems to ensure data quality, and providing incentives to those who are responsible for these processes are essential. Since AAAs are diverse in their operating procedures (e.g., AAAs collecting all the data internally, AAAs subcontracting to other entities for data collection, or a combination of the two), this is perhaps the greatest challenge in that it inevitably requires modifications to long-standing practices and relationships. During our pilot test of an integrated data system, we will work closely with select AAAs to insure that these procedures are well thought out.

1. Current Services Tracking in NAPIS/QSR

a) Quarterly service report (CDA 272). The QSR requests information regarding the number of quarterly service units provided as part of the FCSP for five major service groups: 1) Service Information; 2) Access; 3) Caregiver Support; 4) Respite; and 5) Supplemental Services. The services with an "R" next to them in the first column of the instrument also require demographic profiles to be reported using the companion "Annual Profile Report" (APR).

The primary strengths of the QSR are that it is easy to use, only requires quarterly submission, and provides CDA and the AAAs with a general measure of service effort resulting from funds available for the FCSP. The primary weaknesses of the QSR are that it does not allow CDA or the AAAs to assess the characteristics of clients who use specific types of services; does not provide any measures of service intensity (e.g., the number of service units utilized by a client); does not provide information regarding the total number of unduplicated clients served by the FCSP; and does not provide CDA or the AAAs with measures of service quality based on caregivers' experiences.

4. Services Tracking Capability of Other Systems

A number of existing systems have the capability to track service use at the individual client level, and also generate aggregate data for the population that uses FCSP services.

a) CRCs. CRCs collect quarterly data on caregivers, care recipients, services and expenditures via the CRC Uniform Services Automation System. The CRC Services Automation System and Caller/Caregiver Provider Tracking System (CCPTS) include data collection reporting requirements on all clients served, date of service, service mix, and case status. Major data components include the following:

- Information on individuals completing the CRC intake process (e.g., the total number of callers, caller ethnicity and a summary of the callers' identified needs);
- The number of family caregivers served and average service mix during the fiscal year;

- The units of service (i.e., amount of service) for each service provided to family caregivers during the fiscal year;
- Expenditures for voucher services as reported in the CRC Services Automation System; and
- Co-payments for respite services paid by family caregivers.

b) SF-GetCare. The SF-GetCare project includes a web-based Consumer Assessment, Referral, and Enrollment (CARE) tool, for recording, tracking, managing and reporting information on Department of Aging and Adult Services (DAAS) consumers and the services they receive. The CARE tool is integrated with an Online Multi-Agency Case Management System, which combines information from all major CBLTC programs and develops a web-based system to allow service programs serving the same individual to coordinate care by sharing assessments, care plans and progress notes, with the consent of the consumer.

c) Q Continuum Management System. The Q Continuum Management System includes individual-level service unit tracking as part of its online approach for collecting client data across various health and human services agencies.

d) KSSP. The KSSP data system tracks all significant encounters with the grandparent caregiver, child or family member that is participating in the program on a weekly basis.

E. Impact Analysis

Assessing and incorporating consumer feedback are important components of any quality assurance effort. However, programs seldom assess actual program activity outcomes, even though monitoring program outcomes can affect programs positively by describing their impact on target populations. Furthermore, information on program outcomes can be used both internally to continually improve programs and externally to justify resources allocated to programs.

Our primary recommendation involves a PSA-based examination of client experiences from a representative sample of caregivers who have used FCSP services. Areas to be examined include service satisfaction as well as perceived client-level outcomes associated with service use.

1. PSA-Based Client Satisfaction Profile

Using the common data set as a master file, AAAs or the CDA should extract a random sample of clients (selection could be based on selecting clients whose SSN ends in 0 or 5; or birth dates ending in 0 or 5) who utilized FCSP services, as a basis for a follow-up survey to assess client satisfaction with caregiver support services.

Consumer satisfaction is a complex, multifaceted concept, which can be difficult to assess in an unbiased manner. Specific, directed measures of components of client satisfaction have been shown to provide a more meaningful assessment of satisfaction than a global rating which collapses multiple dimensions of satisfaction into a single judgment. For example, using information drawn from the client tracking system, caregivers could be asked about their experiences with each of the services they utilized during the target timeframe. Specific questions might address the adequacy of the services offered, their timeliness and availability, the competence of service providers, cultural or linguistic barriers, any problems obtaining needed assistance, recommendations for improvements to enhance services or remove barriers, etc. An example of a validated service satisfaction tool that could be adapted to meet the needs of AAAs is the Home Care Satisfaction Measures (HCSM) (Geron et al., 2000). The HCSM-CM13, for example, assesses satisfaction with care management services, including competency, service choice, positive interpersonal contact, and negative interpersonal contact.

2. Client-Level Outcomes.

Individual-level outcomes of service use also should be assessed in conjunction with the PSA-Based Client Satisfaction Profile described above. Consumers would be asked to evaluate whether the use of specific services resulted in any changes with regard to areas such as the following:

- Knowledge of available services
- Attitudes about using services
- Support from informal sources
- Physical strain
- Financial hardship

- Emotional stress
- Depression
- Sleep
- Conflict between work and family
- Family conflict and communication
- Care recipient functioning
- Perceived ability to provide quality care

A more rigorous approach would involve comparing client levels on each of these domains after service use with their levels prior to service use, preferably in comparison to caregivers who have not used those services. Such an analysis might be conducted on a limited basis, perhaps building upon data or measures from the California Statewide Survey of Caregivers (Scharlach et al., 2003). However, given the services available with current FCSP state-wide funding levels and the lack of intensive intervention targeting, it may be difficult to demonstrate measurable impact using standard, non-specific outcome measures.

3. Current Impact Analysis Efforts

a) Performance outcomes measures project (POMP). The Administration on Aging (AoA) has initiated an effort to develop and field-test a core set of performance measures for state and community programs operating under the Older Americans Act (OAA). Entitled the Performance Outcomes Measures Project (POMP), this initiative helps State and Area Agencies on Aging address their own planning and reporting requirements, while assisting AoA to meet federal accountability provisions.

Currently, the project has developed measures for eight client-service domains, among other areas of performance:

- Physical Functioning Revised Katz Activities of Daily Living (ADL) scale
- Nutritional Risk Nutrition Screening Initiative (NSI) and several additional questions
- Caregiver Well-Being Questions on Caregiver Support & Satisfaction

- Emotional Well-Being Questions on mood and affect from prior surveys of the elderly
- Home Care Satisfaction Questions from the Home Care Satisfaction Measure (HCSM)
- Transportation Measures client's satisfaction with transportation services
- Information & Assistance Measures client's satisfaction with I&A support and service referrals
- Social Functioning Degree of contact with others and satisfaction with social activity

The caregiver performance measure contains modified questions from the Long Term Care Survey that address the personal satisfactions and burdens associated with providing care for someone else, but only limited questions regarding the perceived impact of AAA-sponsored services.

b) CRCs. Information and data are collected from three sources:

- The CRC Uniform Services Automation System and Caller/Caregiver Provider Tracking System (CCPTS) include data collection reporting requirements on all clients served, date of service, service mix, and case status. The CRC system is currently implementing an Integrated Client Record Tracking System (ICRTS) – a statewide Internet-based computer system that will record information on clients, assessment data, date of service, service mix, vouchers, waiting lists, mailing lists, and staff schedules. With the new ICRTS, information will be stored on a central server, thereby making both system-wide and individual site reports attainable.
- Quarterly Progress Reports include CRC progress on staffing and administrative functions; the documentation of any new unmet needs identified regionally; and activities and accomplishments in five strategic plan objectives.

- Family caregiver assessment data, reassessed at six-month intervals, examines changes in the caregiver's situation, the impact of services, and on-going service needs. The Assessment Tool contains information on six caregiver domains: knowledge, support, burden, depression, behavior management, and institutionalization.

c) KSSP. The KSSP data system includes some pre- and post-measurements for caregiver and child health and family needs. The measures have been translated into Spanish, Vietnamese and Chinese.

A KSSP Satisfaction Form available from the Center for Social Services Research at the University of California, Berkeley, examines caregivers' opinions about the kinship support services they received and their impact. The form collects information about the overall quality of the services, how quickly they were provided, whether they impacted the child and caregiver's general needs, and whether they contribute to the stability of the caregiving situation.

4. Pilot Test

In collaboration with select AAAs, an integrated data system will be developed in order to examine impacts of caregiver service utilization. The pilot phase will involve a relatively small number of AAAs, in order to insure that CDA and AAA staff are not overwhelmed with the additional work that will be required to implement the system and conduct the testing procedures. Participating AAAs will develop (or already have) the capability to electronically track individual service users, including demographic characteristics, baseline assessment, and service utilization. AAAs also will develop (or already have) the capability to collect follow-up data regarding consumer satisfaction and caregiver and care receiver outcomes.

F. Conclusion

An integrated caregiver information system would consist of three components: (1) a Profile of Caregivers and Care Receivers, including local, regional, and statewide information regarding the characteristics and needs of a representative sample of caregivers; (2) a PSA-Based Client-Specific Data and Service Use Common Data Set, incorporating client-specific information on caregiver and care receiver characteristics with unduplicated counts of service utilization for caregiver support services; and (3) a PSA-Based Client Satisfaction Profile, including service satisfaction and client outcome information from a representative sample of clients using caregiver support services.

The implementation of any or all of the information systems proposed here will be contingent on the practical realities of interest, time and funds to support such efforts. It is clear that for a caregiver information system to have greater utility than currently is the case, an additional investment of resources is necessary. While the assessment of the costs and benefits of various options presented herein ideally should be assessed by CDA with consultation from the AAAs, the recommendations provide a context for discussing alternative scenarios. For example, the caregiver profile survey might be conducted every four years to reduce costs. Similarly, the client satisfaction profile may be implemented every two years. Alternatively, CDA may decide to improve the client-level reporting system initially and consider phasing in other components as resources permit.

In-depth decisions about specific data systems should proceed from a consideration of what components of the system, if any, would enhance the ability of CDA and the AAAs to meet the needs of California's family caregivers. Included in this evaluation should be a consideration of the interface between CDA, AAAs, CRCs and other caregiver support systems, including the special needs of grandparent caregivers.

IV. BUILDING A COMPREHENSIVE CAREGIVER SUPPORT SYSTEM IN CALIFORNIA

A. Characteristics and Limitations of the Existing System

1. Planning and Coordination

Under the Older Americans Act, Area Agencies on Aging are charged with planning and coordinating local services for older adults and their caregivers. For the most part, AAAs have integrated caregiving into their overall planning efforts, although there is substantial variation across PSAs, and some AAAs are not necessarily seen as the entities with primary responsibility for planning and coordinating local caregiver resources. Some planning is systematic, including a careful assessment of local caregiver needs, while in other cases it is incremental.

Coordination is mostly directed at Title III-E contractors, although some PSAs have initiated efforts to include a broader range of providers of supportive services for caregivers. There appears to be relatively little coordination of grandparent kin-carer support efforts, which involve county Departments of Social Services as well as AAAs and other organizations.

The California Department of Aging is charged with planning and coordinating statewide Title III-E efforts. The state Long-Term Care Council (LTCC) has identified caregiving as a priority area; however, there has been little apparent statewide planning or coordination so far. The LTCC's current Olmstead planning activities provide an opportunity to address family support as part of a broader effort to assist disabled individuals to live in the most integrated setting appropriate to their needs.

2. Providers

California has a wide array of caregiver support providers and types of support services. Caregiver Resource Centers offer the most comprehensive array of support services for family caregivers, primarily directed at those caring for persons with adult-onset brain impairment; services include information and referral, long-term care planning, legal and financial consultation, counseling, support groups, education and training, *Link2Care*: an Internet-based information source, and respite care. AAAs primarily provide information and assistance, along with community education and outreach, although some AAAs offer case management and other direct services.

Adult Protective Services provides counseling and case management for families of older adults at risk of abuse or neglect. IHSS pays family members and other informal caregivers to provide personal care to low-income elders and provides some training for caregivers; it also offers respite for family members, both directly and indirectly.

Older adults caring for children have a considerably smaller array of services available than do family caregivers of older adults. The primary grandparent kin-carer support program is the Kinship Support Services Program (KSSP), which offers peer mentoring, parenting education, support groups, case management, health assessments, nutrition counseling, transportation assistance, and emergency tangible goods for relative caring families. Grandparents as Parents (GAP) consists of small autonomous groups established and led by health or social service providers, or by grandparent caregivers themselves. In addition, the DSS foster care program provides financial support for low-income families caring for children.

Health care providers are identified by caregivers as their most frequent source of support, especially for education, information, and counseling. Disease-specific programs, such as the Alzheimer's Association and the American Cancer Society, primarily offer information and assistance, along with some caregiver education and training, and support groups. A wide variety of organizations offer local support groups or day respite, and residential care providers are an important source of overnight respite. Clergy, mental health counselors, and other professionals provide counseling, whether emotional, pastoral, financial, or legal.

Family and friends are the primary sources of support with regard to in-home respite, overnight out-of-home respite, and emotional support from peers. Caregivers also increasingly are obtaining information and advice through the internet, and from the public media. Finally, many programs designed for elderly or disabled persons (e.g., home care, day care, rehabilitation) benefit family caregivers directly as well as indirectly.

3. Funding Sources

The largest single source of financial support for family caregivers in California is IHSS, approximately 70% of whose clients are receiving personal care from family members or other informal caregivers paid through the IHSS or Personal Care Program. IHSS, which is administered by CDSS, is funded primarily by federal Medi-Cal dollars, with additional SGF funds for the state match and the Personal Care Program. The Family Caregiver Support Program, administered by CDA and provided by local AAAs or their contracted service providers, is funded primarily by federal OAA Title III-E funds, with a 25% non-federal match. Caregiver Resource Centers, administered by DMH, are funded entirely from SGF. The Kinship Support Services Program, administered by CDSS, is funded primarily by SGF. In addition, there are a variety of secondary programs which assist caregivers either directly or indirectly, funded by a combination of SGF, OAA, and Medi-Cal. Family caregivers themselves also experience substantial financial costs, whether through out-of-pocket expenses, foregone wages, increased health care costs, or reduced pensions.

4. Limitations of the Existing System

California has a wide variety of actual and potential supports for caregivers; however, the lack of local and statewide coordination contributes to a great deal of fragmentation and duplication. Programs often differ with regard to their eligibility requirements, target populations and services, typically based on historical patterns rather than a rational approach to planning. Some groups are apparently well-served (e.g., caregivers for persons with dementia, especially those in certain areas), while others may be less well-served (e.g., caregivers for persons with mental illness).

Some local communities are finding ways to work around existing program barriers. Most AAAs, for example, include CRCs and other major caregiver support programs in their needs assessment and planning process. Many AAAs are contracting with their regional CRC to provide some or all of their Title III-E caregiver support services. But, few AAAs have adopted a coordinated approach involving the variety of services needed by caregivers. In particular, there is relatively little coordination between programs for caregivers and those for elderly and disabled adults, reflecting the fragmented nature of both of these systems.

Many consumers have little awareness that caregiver support programs exist, or how to access them. After family members and friends, caregivers are most likely to turn to health care providers, who by and large have not been included in caregiver planning and coordination efforts, and who typically have neither the time nor the knowledge to provide the assistance that caregivers need.

B. Vision for a More Effective Caregiver Support System

Supporting caregivers requires a broad approach, incorporating multiple funding streams and diverse types of assistance. It is necessary to go beyond existing program boundaries and established service limitations to promote development of a more comprehensive caregiver support system that embraces the diversity of family caregiver needs and possible community resources. Of particular interest are the potential contributions of sometimes-overlooked resources such as religious and communal organizations, health care providers, and non-traditional information sources such as the internet.

A caregiver service network should help to build caring communities and assist caregivers in providing the best possible care, without undue sacrifices. Fundamental goals of the caregiver service network should include improvements in caregiver well-being, including prevention or amelioration of potential deleterious impacts of assisting an elderly/disabled family member, as well as improvements in care recipient well-being, often through enhancing the ability of individuals and their families to provide and/or manage care. A comprehensive caregiver support system also should aim to increase public awareness of and support for family care, including planning for personal and familial care needs, and public knowledge regarding services and informal support for caregivers. Additionally, increased support for caregivers by formal and informal community support structures, including service providers, physicians, churches and employers, is crucial to the success of the caregiver support network, as is increased political support for caregiver support policies and programs. While these goals may be ambitious, they reflect the reality that supporting caregivers requires a broad approach, of which traditional caregiver services may be but one component.

TABLE 10. GOALS OF AN EFFECTIVE CAREGIVER SUPPORT SYSTEM

- Improvements in caregiver well-being
- Improvements in care recipient well-being
- Increased public support for family care
- Increased support for caregivers by formal and informal community support structures
- Increased political support for caregiver-friendly policies and programs

C. Components of a Comprehensive Caregiver Support System

We propose a general framework for California's efforts to support family caregivers. This framework reflects a consideration of the supports that caregivers need, which transcend the specific services covered by Title III-E. While portions of this framework may be beyond the scope of the NFCSP, a comprehensive effort to improve the well being of caregivers and those for whom they care requires consideration of all of these components. Moreover, examples of innovative and effective efforts in each of these domains are available and worthy of consideration. Components of this general framework are included in Table 11.

TABLE 11. COMPONENTS OF A COMPREHENSIVE CAREGIVER SUPPORT SYSTEM

1. Public Education and Awareness
2. Information and Referral
3. Caregiver Identification and Assessment
4. Caregiver Education and Training
5. Support for Vulnerable Caregivers
6. Education for Service Providers
7. Collaboration with Employers
8. Collaboration with Health Care Providers and Other Community Organizations
9. Integrated Information System

1. Public Education and Awareness

Public awareness campaigns designed to promote public recognition and discussion of the prevalence and realities of family care should be conducted statewide as well as locally. Local efforts also can provide information about services available in the local community. Placement of linguistically and culturally appropriate informational materials in local meeting places such as churches, supermarkets, and beauty parlors can be especially effective in reaching underserved populations.

Media partnerships should be established. The PBS special "And Thou Shalt Honor," for example, demonstrated how television can be used to raise awareness about family caregiving. The California Integrated Elder Care and Involvement Act of 2002 (SB 953) calls upon the California Department of Aging to create a joint coalition to work with the entertainment industry in an effort to change cultural attitudes and perceptions of aging and older adults. These efforts could be expanded to also address the concerns of family caregivers.

2. Information and Referral

Caregivers need readily available information regarding supportive services and resources that may assist them to manage the caregiving situation or alleviate the stresses of doing so. Caregivers would benefit from a dedicated, statewide "1-800" number that they could call for assistance. Japan, for example, has a national toll-free Telephone Hotline for Mutual Support of Family Care. In addition, information specialists in existing systems (e.g., AoA Eldercare Locator, 1-800-510-2020, 211) should be trained to recognize caregiving issues and refer caregivers to appropriate resources. The North Carolina Division of Aging, for example, has created a toolkit of information about caregiving and memory disorders for Information and Assistance (I&A) professionals.

The Internet is of increasing importance as a source of information for caregivers. *Link2Care*, developed and operated by Family Caregiver Alliance, provides caregivers with online information and support, including current news regarding public policies and research findings of interest to caregivers, lists of local workshops and events, the ability to pose questions to caregiving, medical, and legal experts, and a moderated discussion group. Web-based approaches such as this can be especially useful in reaching isolated caregivers who may find it difficult to access traditional support services during normal business hours due to geographic barriers, employment, or the demands of their caregiving situation. On-line support groups, moreover, may help to alleviate caregivers' social isolation and emotional distress.

3. Identification and Assessment

Assessment of caregiver needs and resources should be an integral part of care planning and service delivery efforts in all home and community-based care programs (e.g., IHSS, MSSP, Linkages), child care programs, and health and mental health programs serving vulnerable individuals. In effect, there should be "no wrong door" by which caregivers can enter the service delivery system. Programs should include family members in the assessment and care planning process whenever possible, and should assess family members' needs for support and training. This will require that health, long-term care, and child care professionals and paraprofessionals receive training regarding identification and assessment of caregiver needs and information about available community resources for caregivers.

4. Caregiver Education and Training

Caregivers and AAAs identify education and training as a major unmet need, including training in specific caregiving tasks, education about disease processes, and problem solving and coping techniques. Education and training for family caregivers should be an explicit component of programs serving elderly and disabled persons, health and mental health services, and caregiver-specific support programs. The state's New Freedom Initiative Real Choices Program grant for training IHSS workers, 70% of whom are informal care providers, affords an important new resource for caregiver training.

5. Support for Vulnerable Caregivers

Intensive intervention efforts should be targeted to those caregivers who experience high levels of physical strain, financial hardship, depression, family distress, work-family conflict, or other negative outcomes. Caregivers who are especially vulnerable include those who care for someone with problematic behaviors, dementia, or a high level of daily dependency, or who are poor, socially isolated, or have health problems of their own.

Targeted intervention efforts should be based on an assessment of caregiver needs, as part of a plan of care. Interventions typically should include a combination of individual and family counseling, support, and education, as well as assistance in accessing these and other community support services. Problem-solving and behavior-management skills training have been shown to be especially effective with specific problems, while family counseling can reduce family conflict and improve communication. Disease-specific support groups can reduce isolation and encourage cross-learning among caregivers with similar care situations. Respite care, whether in-home or out-of-home, provides temporary relief that may be most effective when offered relatively early in the caregiving process and on an ongoing basis.

Grandparents caring for young children with physical or behavioral problems are particularly vulnerable, yet have few resources targeted to their needs. Promising initiatives worth replicating in California include mini-grants to facilitate development and operation of new grandparent support groups, vouchers for purchasing respite care, intergenerational health and social services where grandparents can receive care for themselves as well as their grandchildren, assistance in accessing financial support through CalWorks and Kinship Guardian Assistance payments, legal assistance regarding the foster care system, and the development of intergenerational housing designed to accommodate the needs of grandparent caregivers and their families.

6. Education for Service Providers

Providers of health and mental health services for caregivers are an important component of the caregiver support system. However, for the most part, these professionals have little knowledge or expertise regarding the needs of caregivers, and typically are not even aware of the caregiving responsibilities of their patients. Efforts should be developed to work with professional associations and educational organizations to assure that health and long-term care professionals and paraprofessionals receive training regarding the identification and assessment of caregiver needs as well as information about available community resources for caregivers. Professional training and continuing education in gerontology required under the California Integrated Elder Care and Involvement Act of 2002 (S. 953), for example, could include a module on family caregiving.

Home care providers and other components of the CBLTC system provide important secondary support for family caregivers, yet formal and informal support efforts seldom are coordinated in an organized fashion. Dramatic increases are required in the number of home care providers available to assist elderly and disabled persons, as well as major improvements in their training and skills. OAA program staff and other senior service providers also would benefit from training regarding caregivers' needs and services. Housing workers would benefit from education regarding the rights of grandparent-headed families and the environmental supports needed by disabled older adults and their caregivers. The Caregiver Adaptations to Reduce Environmental Stress (CARES) project, funded by AoA and administered by University of Southern California's Andrus Gerontology Center, for example, will provide AAAs and other organizations with online training and technical assistance to conduct environmental assessment and home modifications in caregiving households.

7. Employers

Given that the majority of caregivers are in the work force, employers have an important role to play. Indeed, the past ten years has seen tremendous growth in the quantity and quality of workplace policies and programs designed to assist employees with their elder care responsibilities. Employer-sponsored initiatives designed to assist employees with their elder care responsibilities include leave policies, "flexible" (i.e., non-traditional) work arrangements, informational programs and materials, counseling and referral programs, financial assistance, direct assistance with caregiving, and community resource building. Moreover, California's recently-enacted paid family leave provision is an important new resource for working caregivers. These initiatives have the potential to not only relieve some of the stress experienced by caregivers but also improve community social infrastructure while enhancing corporate productivity.

AAAs and local community organizations should seek ways to collaborate with employers to enhance support for employees who have family care responsibilities, and to inform employed caregivers regarding the resources available to them. Community-employer partnerships, such as the Los Angeles Elder Care Resource Network and One Small Step, can help employees to access information and services, while reducing the need to take time off during the work day. AAAs can serve as model employers by offering family-friendly policies and benefits for their employees. In addition, consideration should be given to tax incentives to encourage employers to develop programs to assist caregiving employees and community members.

8. Health Care Providers and Other Organizations

Health care providers are the formal resource utilized most frequently by family caregivers. Indeed, medical practices in the United Kingdom are required to have a system in place for identifying caregivers and documenting their needs. Primary care physicians play a central role in diagnosing illness in older adults and coordinating care, and are a natural first source of information and assistance for family caregivers. Physician office staff and other health care personnel should be provided informational materials about caregiving for distribution to patients and their families, as well as an easy-to-use guide to local caregiver support resources. Special attention should be given to family members at critical transition points in the health care process, such as hospital discharge, nursing home admission, or the diagnosis of Alzheimer's disease.

A number of hospitals and other health care organizations have increased their level of services for family caregivers in recognition of the toll of caregiving on members' health and the important role family caregiving can play in reducing health care costs. For example, the Health Education Centers of the Kaiser Permanente Medical Centers include information and referral services and other resources specifically for caregivers. With support from the United Hospital Fund, Mount Sinai Medical Center in New York City has developed a Caregivers and Professionals Partnership (CAPP) Program, which includes a Caregiver Resource Center, an education program for caregivers and staff, and performance incentives to increase institutional responsiveness to caregiver issues. Given current budgetary pressures, permanent adoption of such programs by HMOs will require evidence of cost-effectiveness.

Efforts also should be made to enhance the capacity of other community organizations and natural communities to support their members and clients who have caregiving responsibilities. Churches, fraternal organizations, ethnic community groups, and other naturally-occurring organizations can play an important role in local efforts to identify and serve otherwise hard-to-reach caregivers.

9. Integrated Information System

An integrated CDA-AAA caregiver information system should be developed, consisting of three components: 1) a Profile of Caregivers and Care Receivers, including local, regional, and statewide information regarding the characteristics and needs of a representative sample of caregivers; 2) a PSA-Based Client-Specific Data and Service Use Common Data Set, incorporating client-specific information on caregiver and care receiver characteristics with unduplicated counts of service utilization for caregiver support services; and 3) a PSA-Based Client Satisfaction Profile, including service satisfaction and client outcome information from a representative sample of clients using caregiver support services.

D. Items Requiring Further Consideration

1. Target Population(s)

California's current caregiver programs are targeted primarily towards (1) individuals caring for elders 60+; (2) families caring for brain-impaired adults; and (3) elders caring for children. But, other caregivers also have critical needs for assistance, including counseling, support groups, legal assistance, training in care provision, and respite. Moreover, family members who care for non-elderly disabled adults and children often experience especially great challenges, and the majority of grandparents caring for grandchildren are under the age of 60, and thus not eligible for support under Title III-E. Unlike California, caregiver support programs in most other states serve families with a broad spectrum of care situations. With this in mind, consideration should be given to expanding current programs to include families caring for adults and children with all types of disabilities, and non-parental relatives of all ages who have primary care responsibility for young children.

2. Local Coordination

California's diverse array of caregiver support resources is marked by inconsistencies and inequities which contribute to service gaps and inefficiencies. Better coordination and collaboration are needed locally and statewide.

At the local level, caregiver planning consortia should be established to improve community supports for caregivers, through community planning, coordinated service delivery, and case discussion. These consortia should include representatives of the major local caregiver service providers and advocates, such as AAA, CRC, Alzheimer's Association and other disease-specific organizations, KSSP, adult day programs, health care providers, religious organizations, and other relevant community representatives. Particular efforts should be made to improve coordination with community-based long-term care services for family caregivers, and between DSS and AAA services for grandparent kin-carers.

Local caregiver planning efforts should, wherever possible, be an integral part of local long-term care coordination initiatives. Los Angeles County, for example, is developing a Long-Term Care Coordinating Council to help implement and monitor the county's new long-term care strategic plan, one of whose seven goals addresses caregiver and kinship services. The Council is composed of representatives from county, provider, community and consumer groups, including DHS, DMH, DPSS, DCFS, CIO, Commission on Aging, Women's Commission, Disability Commission, Human Rights Commission, Mental Health Commission, PASC, and other relevant county and community groups.

3. Statewide Coordination

Better coordination across relevant state departments and programs can help to increase efficiency by reducing service fragmentation and duplication. A statewide caregiver planning council, representing the major state departments and statewide programs serving caregivers, should be convened, perhaps under the auspices of the Long-Term Care Council. The state of Maryland, for example, has established a statewide Caregiver Coordinating Council, and Kansas has a grassroots Kansas Caregiver Coalition. In California, the LTCC, composed of directors of CDA, DMH, CDSS, DD, and other relevant departments, is best positioned to oversee a statewide approach to meeting the needs of California's caregivers.

Family support should be an explicit objective of all state long-term care policies and programs, including Olmstead planning, the Strategic Plan for an Aging California (SB 910), AB 43, and other local long-term care integration and coordination efforts. Too often, policies and programs for persons with disabilities give scant attention to the needs or capability of family members; indeed, some policies and programs explicitly state that they are "not to be provided for the convenience of family."

Caregiver support efforts throughout California also can benefit from improved access to existing knowledge and cross-learning about effective practice models. The California Association of Area Agencies on Aging and the California Department of Aging can assist AAAs to share their experiences in developing and implementing caregiver support programs in their local communities. In addition, Family Caregiver Alliance, as the Statewide Resources Consultant, can play an important consultative role by providing technical assistance that can enable local and statewide agencies to develop caregiver programs that reflect the latest knowledge and expertise nationally. Other useful resources include culturally-specific organizations, such as the Asian Community

Center of Sacramento Valley, which has an AoA grant to improve services for Asian and Pacific Island caregivers.

4. Funding

Congressional appropriations for Older Americans Act Title III-E are an important first step in assisting the nation's caregivers; however, they are only a first step. Indeed, federal support for caregiver programs in other countries such as Australia is more than ten times as great as in the United States, on a per capita basis. Even in the current fiscal environment, appropriations for Title III-E should be increased or at least sustained.

Substantial state resources currently flow to programs which support caregivers, whether directly or indirectly. Additional funds should be sought from private funders, especially to provide support for populations and services not covered under OAA Title III-E. The California HealthCare Foundation, for example, has provided critical support for the Communities Creating Long Term Care Options planning initiative.

In addition, there could be considerably greater transparency regarding current state expenditures, so as to improve central planning and alleviate perennial concern regarding the state's ability to provide its 25% match for federal OAA Title III-E funds. Some states have treated caregiver support funds as a single pool, regardless of source, so that funds can be expended in a manner that most closely reflects caregiver needs.

5. Advocacy

California's caregivers have no simple mechanism by which to influence the development of local programs and policies that reflect their needs and concerns. Nor is there a primary statewide agency or organization charged with representing caregivers' interests.

Affirmative efforts should be made to actively involve caregivers and their representatives in local and statewide planning activities. In addition, encouragement should be given to development of a single statewide entity charged with representing and advocating for the needs and concerns of caregivers. This could be an existing organization, or a coalition of major statewide organizations concerned about caregivers. Joint advocacy efforts in some states have emerged as part of lifespan respite initiatives.

6. Quality Assurance

Evidence is needed regarding the effectiveness of current efforts to assist caregiving families. Such evidence is essential for assuring that programs are cost-effective, and that families receive the specific types of services from which they are most apt to benefit. In addition, evidence of program outcomes is legislatively mandated and an important prerequisite for assuring continued funding of state and federal caregiver support programs.

Despite anecdotal reports of the potential benefits of caregiver support programs, empirical evidence regarding their effectiveness is woefully lacking. Also needed are studies of the secondary effects on families of community-based long-term care initiatives targeted to disabled adults, to assess whether and in what ways long-term care integration, MSSP, and other initiatives affect the demands on caregiving family members.

The Profile of Caregivers and Care Receivers, PSA-Based Client-Specific Data and Service Use Common Data Set, and PSA-Based Client Satisfaction Profile envisioned in section III of this report are a requisite feature of any systematic statewide effort to assure the quality of California's caregiver support programs.

E. Conclusion

California, home to Family Caregiver Alliance, Caregiver Resource Centers, and Edgewood Center's Kinship Support Network, is one of the few states to have substantial experience and expertise in providing caregiver support services. The basic building blocks upon which to develop a more comprehensive system of support for family caregivers in California appear to be in place. Although the role of Area Agencies on Aging in the caregiver service network is not yet fully developed, the National Family Caregiver Support Program provides them with opportunities to expand services to meet the diverse and complex needs of caregivers. However, Title III-E funds cover only a portion of the overall set of community resources for caregivers of adults over age 60 and grandparent caregivers. A more comprehensive caregiver service network requires collaboration and coordination among formal and informal networks, including public and private entities, as well as leadership from state and local governments.

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VI. APPENDIX A

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