

**Planning for Older Americans Act Funding to Support Family Caregivers
Final Report**

Prepared for

The West Central Florida Area Agency on Aging, Inc.

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Executive Summary

The Older Americans Act Title III-E National Family Caregiver Support Program provides support services for family caregivers and grandparents or to older individuals who are relative caregivers. The program encourages the provision of multifaceted systems of support services to assist individuals in providing care to older family members, adults with disabilities, and children. The goal of the program is to relieve emotional, physical, and financial hardships of individuals providing care. The primary consideration is for the caregiver.

Research

Family members provide the majority (80%) of caregiving in the United States. Even though family members may be available and agreeable to be caregivers, many may not be able to provide adequate care for a disabled adult, a frail older adult, or a child. For this reason, family members providing direct care are in need of easily available and affordable support services. The physical, financial, educational, and psychological services are required not only as a contribution to the care of the care recipient but, equally important, to care for the caregiver. Criteria for services are often based on risk factors and functional ability. Those who do not meet the criteria are usually placed at the bottom of the list. Intervention needs to begin in early stages of caregiving. For instance, if a caregiver is educated about ways in which to provide care as well as the support services that are available in the community, and has access to those services, the family may continue to play an important role in caregiving.

Previous research has found that caregivers need assistance with providing care, respite, education, and financial assistance. Within each of these areas, the research literature has identified specific aspects to be addressed.

Assistance in providing care:

- Assist with personal care of the care recipient.
- Help with chores in the home.
- Provide transportation and shopping services.

Respite:

- Affordable.
- Include in-home respite, as well as adult day care and short-term residential placement.
- Provide transportation.
- Include medical care, rehabilitation therapy, and mental health services for participants and their families at day care and residential settings.

Education:

- Family caregiver training.
- Service provider training.

Financial Assistance:

- Increase the amount of subsidies paid to families who provide care to relatives.
- Provide tax incentives for family caregivers.

Key Informants

Key informants selected from traditional and non-traditional service providers, identified a diverse need for services. Providers have programs that fall into nearly every Title IIIe Guideline category-- information, eligibility, counseling and support, respite, supplemental services, grandparents caring for grandchildren—but not older adults caring for family members with MR/DD. According to providers, respite is the number one requested service program from caregivers. Caregivers need in-home, facility-based, overnight and weekend respite and subsidized day care. Currently, providers offer these programs as well as financial reimbursement for respite services, yet many of the services are limited. Providers listed transportation as the second most important need for caregivers, yet no provider answering the survey offers transportation. Still providers agree among other services transportation is needed to help caregivers to continue to give care. Supplemental services are third most important need. This includes: financial assistance, chore services, legal and nursing home planning, meals on wheels, and subsidized in-home professional caregiving to help caregivers to continue to provide care. Current providers offer these supplemental services and, in the future, hope to target underserved populations, train caregivers, increase already developed programs, establish new programs such as statewide kinship care support groups and, in Manatee county, collaborative efforts are currently being explored with the Alzheimer's Association, Tampa Bay Chapter, to provide respite services to caregivers with dementia, expand geographically, and build more Senior Centers.

Focus Groups

Family caregivers identified respite as their number one priority. Many do not receive enough respite services and suggest that adding more hours that include weekends. Also, they prefer direct payments so they can hire a known person that they trust. They need respite in order to take a week's vacation. Many would use residential respite although some had experience with poor care. Stipends were the second priority. They would be used to pay for respite care, in addition to being used for: home modifications, transportation, home expenses, food (Ensure), and adult diapers. Service staff are not reliable nor do they perform their jobs adequately. Caregivers would like access to services that Medicaid clients get---they are just over the eligibility levels. Information was the third priority. They need financial information and how to protect their assets. Information about laws and regulations and eligibility for programs is needed, in addition to timely concrete service information. Transportation was not listed as a priority yet many caregivers expressed a need for this service in the course of the discussion.

Preliminary Recommendations

1. Increase the availability, affordability, and flexibility of respite care. Consider sliding scales so that families that do not meet eligibility requirements can make use of services. Consider direct payment of caregivers for respite so that family and friends can be used. This is especially important for care receivers with dementia who would be stressed by being left with someone unknown to them (or a different caregiver every week). Allow respite for grandparent caregivers and older caregivers of adult children with MR/DD. Offer respite through congregate care facilities including ALF and NH but screen facilities for their capacity to provide dementia care.
2. Consider direct payments to caregivers for other supportive services not readily available through other means (if not on Medicaid) including Ensure, adult diapers, other consumables, and home modifications. Make certain that the payments are adequate.
3. Develop better and more reliable information systems so that caregivers can get concrete information about financial, legal, and personal care services available to them. Regularly advertise a one stop shopping phone number (newspaper, yellow pages) so that caregivers know whom to call when there is a problem.
4. Improve transportation for participants and caregivers. Especially important for making use of off-site respite care (adult day care, senior centers) and for working caregivers.

Research on Caregivers¹

The Extent and Quality of Family Caregiving

Contrary to the common belief in our society that families are abandoning their elderly members to institutional care, research shows that most families struggle to provide care for many years, sometimes resorting to residential placement in the later stages of an illness when they are emotionally and physically exhausted. There are an estimated 52 million Americans who assume the role of caregiver, with one-fifth living in the same household as the care recipient (National Alliance for Caregiving, 1997). Florida is reported to have 1.4 million informal caregivers (Florida Department of Elder Affairs, 2000).

Although there is no universally accepted definition of a caregiver, informal or family caregiving is considered to be that assistance in managing aspects of a person's daily life and/or personal care that is provided by relatives and friends. Studies conducted over the past decade have concluded that informal care is as good or slightly better in quality to formal care in institutions, and that for elders with a relative stable condition, in-home care can be significantly more cost-effective (Hollander, 1999). A recent study conducted in California concluded that people who receive in-home care from a family member or self-appointed caregiver report more positive outcomes than those who receive in-home care from a professional agency, and that the quality of care given by family members was better (Doty, 1998).

Profile of Family Caregivers

The average caregiver is a 46-year-old woman who is a high school graduate with an annual income of \$35,000 and who spends 18 hours a week caring for her 77-year-old mother in addition to working full time according to a survey conducted by the National Alliance for Caregiving (1997). Up to 25 percent care for two or more people. The average length of caregiving is over four years, and the time spent providing care ranges from one hour to over 40 hours per week. More than half of all caregivers (51%) provide assistance with at least one activity of daily living (dressing, bathing, toileting, feeding) and 29% help with at least three. Close to all caregivers surveyed (98%) report that they assist their care recipient with at least one instrumental activities of daily living (preparing meals, grocery shopping, transportation, light housework, taking medications, managing finances, using the telephone), and 81% assist with three or more. Seventy-three percent of caregivers say that other family members or friends also help in providing care.

Caregivers with Special Needs

Minority caregivers. Traditionally, African-American, Hispanic, and Asian families have cared for their aging relatives. However, the economic and social forces that are changing the structure of the family are making it more likely that these caregivers will experience the economic, emotional, and physical stresses of long term care (Angel & Angel, 1997; Cantor & Brennan, 2000) African American caregivers tend to be younger and in poorer health than other caregiver populations. They are also

¹This literature review is taken, in part, from Kaplan (2001). Role of Family Members and Informal Caregivers. In: *Informational Report of the Task Force on Availability and Affordability of Long-Term Care for the Florida Legislature in Response to House Bill 1993*. Tampa, FL: Florida Policy Exchange Center on Aging.

more likely to be children rather than spouses and to be taking care of a relative other than an immediate family member (Bass et al., 1990; National Alliance for Caregiving & AARP, 1997; Knight et al., 2000). African American caregivers have reported lower levels of burden, but in some studies experienced equal levels of depression and other psychological symptoms (Hinrichsen & Ramirez, 1992; Haley et al., 1995; Knight & McCallum, 1998; Knight et al., 2000). Asian and Hispanic caregivers are also significantly younger than Whites, with average ages of 39 and 40, respectively (National Alliance for Caregiving & AARP, 1997). Adult children provide the majority (52%) of caregiving for Hispanic elders (National Academy on an Aging Society, 2000). Asian and African American caregivers are more likely than other caregiver groups to be involved in caring for more than one person. Although minority caregivers experience caregiver burden, they may deal with it in ways that differ from other caregiver populations. African Americans are more likely than Hispanics or Asians to talk with friends and relatives to relieve the stress of caregiving and Asian caregivers are less likely to get professional counseling (National Alliance for Caregiving & AARP, 1997).

Employed caregiver. According to the U.S. Department of Labor (1999), approximately 30 percent of employees have caregiving responsibilities for an elderly relative and 54 percent expect to assume the role of caregiver within the next 10 years. Only six percent of employee benefit plans offer programs for family leave, bereavement leave or help for employees who are coping with a terminal illness or a terminally ill family member. Employed caregivers who require the most support are: females; younger workers; those who have less control in their jobs; individuals with their own health problems; Caucasians who do not have a support system; and those whose caregiving is made more difficult by the difficult behaviors of care recipients.

Caregivers for persons with dementia. It is estimated that there are over 5,000,000 or one in five caregiving households nationwide that provide care for someone with dementia (National Alliance for Caregiving & AARP, 1997). Approximately 70% of persons with Alzheimer's disease, the leading cause of dementia, are cared for in the community by family members (Hodgson & Cutler, 1994). Most Alzheimer's caregivers are forced to miss work, cut back to part-time, take less demanding jobs, choose early retirement, or quit their jobs due to their caregiving responsibilities. As a result, American businesses lose an estimated \$26 billion a year in lost productivity, as well as an additional \$7 billion toward the total cost of care (Alzheimer's Association, 2000). Caring for a relative with dementia often involves providing care for persons with disruptive behavior and functional impairment over potentially long periods of time. Burdens of dementia caregiving include the increasing dependency of the care recipient, strain from other family obligations, occupational responsibilities, and economic problems caused by the high cost of medical and other care. Research indicates that there is an increased risk of stress related problems for families who provide care to persons with dementia (Collins & Jones, 1997; Haley et al., 1995; Irwin et al., 1997; King & Brassington, 1997; Majerovitz, 1995). One in eight Alzheimer caregivers becomes ill or injured as a direct result of caregiving and one in three uses medication for problems related to caregiving (Alzheimer's Association, 2000). In the Canadian Study of Health and Aging (CSHA, 1994), the prevalence of depression in the caregivers of patients with dementia was 25 percent versus 13.8 percent among caregivers of nondemented patients.

Caregivers for developmentally disabled adults. A growing number of adults with developmental

disabilities are surviving to the age when they can expect to experience deterioration in their cognitive and physical functioning (Kaplan, 1996). Advancements in medical care and community programs have contributed to an increase in life expectancy and a greater quality of life for these individuals; the life expectancy for persons with Down's syndrome has increased from 9 years in 1929 to 55 years (Londner, 1992) These individuals experience many of the changes associated with aging at an earlier age and at an accelerated rate. It is estimated that 80 percent of adults with Down's syndrome and other developmental disabilities live with family members (Seltzer et al., 1991). Unlike most caregivers of older adults, caregivers for developmentally disabled adults are most likely parents who have been providing care for decades. As these caregivers reach old age and experience declining health and a shrinking informal support system, they face a critical need for respite services. Persons with Down's syndrome who reach middle age frequently develop the symptoms of dementia associated with Alzheimer's disease (Zigman et al., 1991). Because these individuals do not fit into a rigidly defined target population, they may be denied assistance by aging services as well as by the traditional network of programs and services for younger developmentally disabled persons.

Older adult caregivers of children. The March 1997 Current Population Survey found that 3.9 million or 5.5% of children under 18 live with grandparents and other relatives (Lugaila, 1998). In Florida, more than 250,000 children under 18 live in homes headed by grandparents, an increase of 33 percent from 1990 (U.S. Census Bureau, 2000). The growth of child care provided by grandparents is seen as a result of the recent increase in social health problems, including the substance abusers and HIV/AIDS epidemics, high rates of teen pregnancy, child abuse and neglect, and the incarceration of women of child-bearing age (Minkler, 1999). Custodial grandparents are found in all racial and ethnic groups, socioeconomic levels, and geographic regions. Nationally, 68% are white, 29% are African American, 10% are Hispanic, 2% are Asian/Pacific Islander, and 1% are American Indian (Burnette, 1999; Chalfie, 1994). Child rearing can be challenging for custodial grandparents, who tend to have their own long-term, complex economic, psychological, health and legal needs that span multiple generations (Fuller-Thomson, Minkler, & Driver, 1996; Strawbridge, Wallhagen, Shema & Kaplan, 1997). These issues are likely to be more significant for grandparents of color, as the strain created by their new roles as caregivers are often exacerbated by the cumulative effects of lifelong structural inequalities (Dressel & Barnhill, 1994; Burnette, 1999). Studies of grandparent caregivers have identified a range of needs (American Association of Retired Persons, 1995; Burnette, 1997): financial support; preventive and restorative health and mental health services for children; training in child care and parenting skills; knowledge of laws and regulations that govern placement; respite for caregivers who work; crisis support; issues of visitation, reunification, and permanency planning; and help in accessing services across multiple delivery systems.

The Financial Cost of Family Caregiving

The total annual value of the family caregiving system for all people with long term care needs was estimated at \$196 billion in 1997, more than the total cost of nursing home care (\$83 billion) or paid home care (\$32 billion) (Arno et al., 1999). The economic value of informal caregiving for the state of Florida is reported to be \$10.5 billion (Florida Department of Elder Affairs, 2000).

Caregiving can have a significant financial impact on families. Half of the 500 caregivers in a recent Alzheimer's Association survey reported that they have made financial sacrifices in order to provide care for family members (Alzheimer's Association, 2000). Fifty-nine percent have spent some of their personal income or savings to help pay for care. More than one-third report they reduced their work hours, lost income or have become less productive at work; one in five caregivers gave up their jobs to provide care. The average monthly out-of-pocket expenditure a family caregiver incurs is \$171 (National Alliance for Caregiving, 1997).

The cost of family caregiving to American businesses is also high. A 1997 Metropolitan Life Insurance Company survey of employees who provide care to elderly family members estimated the financial impact of caregiving to both employers and employees to be \$10-30 billion. Included in this estimate are the costs of absenteeism, shortened or interrupted workdays, decreased productivity, supervisor's time, increased health care for caregivers, missed advancement opportunities, and replacing employees. Research findings indicate that between 10-29% of caregivers quit their jobs or accommodate their work schedules to assume care responsibilities (Stone & Short, 1990; Metropolitan Life, 1997). The costs to government and society include reductions in gross national product (GNP) and lost income tax revenue. There may also be increased public expenditures to support caregivers with reduced incomes, benefits such as health insurance, and future retirement benefits (Stone & Short, 1990)

The Physical and Emotional Impact of Caring for Family Members

Caregiving affects the physical, mental, and emotional health of caregivers. The National Alliance for Caregiving and the American Association of Retired Persons (AARP) National Caregiver Study (1997) found that among caregivers who provide care for a family member or friend age 50 or older, an estimated 15% report that they have experienced a physical or mental health problem due to their caregiving duties. Forty-four percent report that their caregiving activities cause physical strain, and 25% report that caregiving is emotionally stressful. Seventy percent of respondents take a positive attitude toward their caregiving duties. Many of those surveyed mentioned resentments about the burden of caregiving or personal sacrifices, but few sought to place their relative in a residential facility in the early stages of impairment. Nonprofessional caregivers have reported more overall stress than their professional counterparts, but also more satisfaction with their caregiving experience (Lawton, 1996; National Alliance for Caregiving & AARP, 1997; Doty, 1998).

Wright, Clip and George (1993) describe the chain of events leading to depression which impacts the immune system resulting in adverse health outcomes for caregivers. Additional research has reported estimates of 18% to 46% of caregivers of elderly relatives to be clinically depressed (Gallagher-Thomson & Steffen, 1994). Increased levels of hostility, anxiety, poorer self-reported health, and compromised immune function have also been found to be associated with caring for a physically or cognitively impaired elderly relative (Schulz et al., 1990; Lawton, 1996; National Alliance for Caregiving & AARP, 1997). In extreme cases of strained caregiver-recipient relations, or when elderly spousal caregivers are coping with their own health problems, abuse or neglect can occur (Sehm & Tully, 1994).

Utilization of Respite and Supportive Services in the Community

Respite care is a service that provides family caregivers with temporary periods of relief and rest from the demands of their caregiving roles. Research has consistently identified respite, as one of the most important unmet needs of caregivers (Lebowitz, 1985; Lawton, Brody & Saperstein, 1991; Hirsch, et al., 1993). Recent studies have been able to document the effects of respite services on caregivers. Caregivers in the Michigan model respite program experienced both increased morale and decreases in their subjective burden (Kosloski & Montgomery, 1995). Deimling's (1991/1992) evaluation of a respite program found that it reduced depression, health problems, and relationship strains among those caring for stable patients. In addition, findings from the Seattle respite study (Kosloski & Montgomery, 1995) revealed that the increased use of respite decreased the likelihood of nursing home placement. For caregivers of persons with dementia, the use of respite at mild and moderate stages of the disease has been shown to delay nursing home placement significantly, at net savings of as much as \$600 to \$1000 a week (Alzheimer's Association, 1998).

Formal support services such as home care and respite programs have been developed to lessen caregiver burden and to encourage the efforts of families to keep their elderly members in their homes for a longer period. However, the existence of services does not ensure that caregivers will utilize them (Boise, 1989; Kaplan, 1996; National Alliance for Caregiving & AARP, 1997). Cost, availability and accessibility, concerns about reliability, cultural traditions, and the receptivity of the person receiving care have been cited by caregivers as factors in the use of support services. Not knowing how to obtain assistance or where to call can also be a major barrier for caregivers. Family caregivers often experience conflict over accepting assistance in providing care (Kaplan, 1996). Many, concerned about criticism by other family members, friends and professionals, see it as a sign of failure. In the National Alliance survey, 74% of the caregivers responding report having used one or more community services. Caregivers of persons with dementia were more likely to report the use of services (83%) and Asian caregivers were the least likely to use services.

An understanding of family dynamics, cultural traditions, attitudes toward and knowledge of community services can help policy makers, program developers, and practitioners to facilitate service utilization. Examining the meanings associated with the use of caregiver support services provides a framework in which the issues that may prevent caregivers from seeking assistance can be understood.

Future Trends in Family Caregiving

- Along with the dynamic changes that our society have experienced in the size, composition and health status of the aging population, we are also seeing transformations in the American family that will affect their ability to provide care for elderly members (Baum & Page, 1991; Cantor, 1991). Due to the increase in life span, multigenerational families are becoming the norm. By the year 2020, the typical family will consist of at least four generations. A recent phenomenon that has emerged is the increasing number of elderly children. Ten percent of those over age 65 have children who are over 65. The elderly child's own physical capacities may be diminishing at the very time when the elderly parent needs assistance. Smaller families are resulting in fewer

siblings to share the responsibility for caring for aging parents. This dilemma is now being faced by China after a generation of government mandated one-child families.

- The increased mobility of our modern society makes daily access to family members impossible. In addition to the frequency of relocation due to career changes by young adults, older adults are often choosing to move to other states when they retire
- The rise of women in the labor force makes caring for a relative in the home a difficult task. Women in their middle years have been the traditional caregivers. Nearly 60 percent of all women between the ages of 45 and 54 are now working. Women are also choosing to marry at a later age and delay their childbearing years, making it likely that there will be an increase in the sandwich generation, that is, women who have responsibilities for younger children as well as aging parents at the same time.
- The increasing incidence of divorce and reconstructed or stepfamilies, and single-parent families have changed family structures and responsibilities. It is not uncommon for adult children to find themselves in the role of primary caregiver for an elderly stepparent.
- Single-parent households (typically female) are not likely to have the time or financial resources to care for a family member.
- Future attitudes about utilizing formal care are still an unknown factor that may influence the role of family members as providers of direct care. For many older adults, such care has been considered as a last resort when family support did not exist or could no longer meet their care needs. With nursing homes no longer being the only alternative available to families, there seems to be a greater willingness to consider turning to appropriate sources of formal assistance.

Lessons from Existing Programs

Research on caregiver programs support the premise that successful caregiver interventions are associated with an increase in both the quality of caregiving and the length of time that a family can provide care for an dependent relative. Psychoeducational programs have produced positive responses from caregivers, and improvements in mood, mental health and caregiver burden (Teri & Zarit, 1991; Lawton, 1996). Research has shown that respite services, which include medical and social model day programs, in-home companion services, and short-term residential placement provide a high quality of care and help to reduce caregiver stress (Family caregiving, 1997; Sehm & Tully, 1994; Rudin, 1994; Doty, 1998). In some studies, respite care has been found to be the most important kind of formal care in the prevention of nursing home placement (Sehm & Tully, 1994). Researchers have also found that there is a need for public assistance programs for caregivers, such as paid family assistance and tax incentives, due to the often overwhelming financial burden of providing care (Doty, 1998; Lawton, 1996; Sehm & Tully, 1994).

In addition to the considerable responsibilities and stress endured by family caregivers, they also

experience problems and frustrations in their encounters with service providers. The primary barriers to obtaining services are availability, access, and cost (Family Caregiving, 1997; Rudin, 1994). The supply of community-based services is limited and has not expanded to meet the needs of the elderly and their families. Restricted policies of eligibility tend to limit access to community alternatives to nursing home care.

Caregivers report that they do not receive adequate information about supportive services or referrals for these services when they take their elderly relative for medical care (Haley et al., 1992). Many primary care physicians and other health care providers have not had specialized training in geriatrics, nor are they knowledgeable about community programs and services.

The following are examples of current programs in other states that provide assistance to caregivers:

California. Services are provided to Latino families in Los Angeles who are caring for a relative with dementia through a grant from the Alzheimer's Association. Developed by the Los Angeles Alzheimer's Chapter and the California Department of Health Services Administration, El Portal (the Gateway) acts as a point of entry to a network of dementia services that are sensitive to the cultural and language needs of Latinos. Through the help of Care Advocates El Portal, families access services from existing programs and social agencies. The program also assists and encourages service providers to develop and implement dementia services within the Latin community.

Michigan. Twelve dementia day care programs have been established through a \$5 million state Senior and Caregiver Respite Fund. The program, coordinated by the state's mental health system, also provides Alzheimer's chapters with funding for information and referral, a dementia education network, and free caregiver education sessions for family and paid caregivers.

Missouri. In the past two years, through ten annual grants of \$25,000 each to Alzheimer's Association chapters, collaborative efforts between public and private partners have resulted in the enhancement of services to persons with dementia and their families. Chapters have opened outreach offices in rural and minority communities, trained volunteer support group leaders, started new support groups in under-served areas, and expanded respite services to families.

Oregon. The School of Nursing at the Oregon Health Sciences University is conducting a caregiver intervention trial designed to increase preparedness, enrichment and predictability in families providing care to older people. The program provides the services of a nurse within a health maintenance organization (HMO) to families caring for an elderly relative. Features of the program, such as home visits, assessments, family counseling and education, have been demonstrated to improve the quality of care provided by family caregivers and to lower the cost of hospitalizations for the care recipient.

Needs Assessment Plan

The Older Americans Act Title III-E National Family Caregiver Support Program provides support services for family caregivers and grandparents or older individuals who are relative caregivers. The

program encourages the provision of multifaceted systems of support services to assist individuals in providing care to older family members, adults with disabilities, and children. The goal of the program is to relieve emotional, physical, and financial hardships of individuals providing care. The primary consideration is for the caregiver. In response to this new initiative, West Central Area Agency on Aging contracted with the Florida Policy Exchange Center on Aging to conduct a review of the research literature and collect key informant and focus group data to understand priorities for family caregivers.

Project Tasks

1. Review recent caregiver literature and conduct key informant interviews with stakeholders, including: AAA staff, conventional providers, alternative providers, caregivers, and community leaders. The focus of the key informant interviews is to determine the need for caregiver support in the five county region for West Central AAA and to identify both conventional and novel solutions to providing support to caregivers across the lifespan.
2. Develop a profile of clients in the five county region for West Central AAA in terms of level of disability, caregiver availability, and other key long-term care indicators. Using data available from CARES, CIRTIS, and Medicaid, we will provide a profile of the current clients who use publicly-available long-term care services.
3. Conduct caregiver focus groups (a total of three English-speaking groups in Tampa (Hillsborough County), Bradenton (Manatee and Hardee Counties), and Lakeland (Polk and Highlands Counties) and one Spanish-speaking group in Tampa) to get responses to the ideas in interim report #1 and make suggestions for ways to best support informal caregivers in the community.
4. Disseminate preliminary recommendations to stakeholders, Senior Centers, press/media, etc. in preparation for Public Hearings.
5. Conduct public hearings (one each in Tampa, Bradenton, and Lakeland to serve all 5 counties) to respond to preliminary recommendations.
6. Develop an evaluation plan that will provide a blueprint for evaluating the effectiveness of implementing the final recommendations. The actual evaluation would be provided under a separate contract and is not included in this proposal.

Demographic and Need Data

The Florida Policy Exchange Center on Aging has an ongoing contract between the State Data Center on Aging at FPECA and Florida Medicaid to build a decision-support system for program evaluation and policy-related research using data in administrative databases from the Florida Agency for Health Care Administration, Florida Department of Elder Affairs, Florida Department of Health, and the Center for Medicare and Medicaid Services.

The CARES and CIRTS databases are maintained by the Florida Department of Elder Affairs. These databases include evaluations of functional status, mental impairment, chronic health conditions, nutrition, and social support for Florida elders who are candidates for long-term care in a nursing home (CARES) or who receive home- and community-based services administered by DOEA (CIRTS).

The State Data Center on Aging (SDCA) is a unit within the Florida Policy Exchange Center on Aging. The SDCA has an on-going contract with Florida Medicaid to provide a decision-support system (sometimes called a “data warehouse”) to help provide Florida policymakers with accurate and timely information on Florida’s long-term care population. As part of that contract, the SDCA links administrative files from Florida Medicaid, Florida Department of Elder Affairs, and Florida Department of Health. For this contract, administrative records from Florida Medicaid claims files were linked with DOEA CARES records for clients receiving services through ALE Waiver, ADA Waiver, HCE, ADI, CCE, and OAA. Long-term care nursing home residents were included as a comparison group.

SDCA staff use a technique called probabilistic record matching to link data files. Probabilistic record matching is a statistically sound technique for matching data across different databases. The technique considers the reliability of the information used to link records. It can compensate for errors in data collection and recording, such as transpositions of characters, errors in entering dates, and reversals of names. It can also compensate for common misspellings, such as “White” for “Whyte”. The technique uses multiple passes combined with clerical review of candidate matches to increase the number and improve the quality of matches.

Disability levels for the 70+ population in the two Counties were estimated using the 2000 Census and age- and sex-adjusted disability rates developed from the Florida oversample of the national survey, Assets and Health Dynamics of the Oldest Old (AHEAD).

Key Informant Survey

A list of key informants was identified by the Area Agency on Aging and included staff from lead agencies providing services to caregivers, as well as alternative service providers. Key informant interviews were conducted in person and by telephone during the months of July and August 2001, using a survey form. Twelve community service providers were contacted and asked to participate in the survey. The purpose of the key informant survey was to identify existing programs and services for caregivers and to determine caregivers’ needs that were currently not being met by service providers.

Focus Groups

Four one-time 90-minute focus group interviews were conducted with small groups of 8-10 family caregivers that were tape recorded and later transcribed. One focus group was conducted in Spanish. Focus group participants were asked to describe the challenges of providing quality care at home, their need for support, and the dynamics of their caregiving relationships. Particular emphasis was placed on investigating what public programs would most support them to provide quality of home care and help to reduce caregiver stress and burden.

Findings

Client Characteristics

The 2000 U.S. Census of the Population reports that there are 225,644 individuals over the age of 70 in Hardee, Highlands, Hillsborough, Manatee, and Polk counties (Table 1). Using age- and sex-adjusted disability rates from the Florida oversample of the AHEAD survey, approximately 29% of this population, or a total of 66,020 needs assistance with one or more activities of daily living. Historically, families have provided long-term care to 80% of elders who need assistance. Given this, a minimum of 13,204 elders will need assistance with personal care. Among those who are likely to be getting help from family (52,816), there is a great need for support of these family caregivers as documented in the national research literature and in the key informant interviews and focus groups described below.

Table 1
Estimated Disabled Population: Needing Assistance with 1+ ADL

	Males				Females				Total	% of 70+	% of Tot Pop
	70-74	75-79	80-84	85+	70-74	75-79	80-84	85+			
Hardee	94	94	61	47	135	124	81	119	756	0.28	0.03
Highlands	679	731	576	456	1002	1028	805	947	6,225	0.28	0.07
Hillsborough	2397	2407	1965	1720	4218	4179	3679	5085	25,650	0.30	0.03
Manatee	1403	1528	1251	1143	2301	2265	2059	2778	14,728	0.29	0.06
Polk	1977	2024	1488	1242	3112	2950	2490	3378	18,662	0.29	0.04

Clients receiving services through the Alzheimer’s Disease Initiative (ADI) and Home Care for the Elderly (HCE) programs are as or more impaired than clients served through the two waiver programs: Aged and Disabled Adult Waiver (ADW) and Assisted Living for the Elderly Waiver (ALW) in counties where these options are available (Tables 2-6). For example, in Hardee county, ADI clients need assistance with 4.43 ADLs on average and HCE clients need help with 2.94. Clients in the ADW program need help with 2.28 ADLs. In comparison, nursing home clients need help with 4.68. As expected, nearly all ADI and HCE clients have a caregiver at home but so do ADW (35%) and some CCE clients (25%). In fact, Older Americans Act program (OAA) clients are less likely to have a caregiver at home (19.5%). They are also the least impaired in ADLs. Hardee County did not have clients receiving ALW services who had a recent evaluation.

Table 2
 Clients Meeting NH Eligibility Requirements by Long-Term Care Program: Hardee County

	NH	ADI	ADW	ALW ³	CCE	HCE	OAA
Average Number of ADLs ¹	4.68	4.43	2.28		1.38	2.94	0.73
% Living with Caregiver	8.00	100.00	35.08		25.00	96.88	19.51
% Meeting Medicaid NH Eligibility Requirements²							
Some help with 5+ ADLS	72.00	71.43	12.28		13.10	28.13	3.25
Some help with 4 ADLS + supervision of medications	0.00	0.00	10.53		3.57	12.50	.81
Total help with 2+ ADLS	0.00	0.00	1.75		1.19	0.00	.81
Alzheimer’s Disease diagnosis or other dementia and require some help with 3+ ADLS	4.00	0.00	5.26		1.19	9.38	2.44
Remaining clients (includes clients with degenerative disease needing nursing care)	24.00	28.57	70.18		80.95	50.00	92.68

¹ ADLs include bathing, dressing, eating, transferring, toileting, and walking.

² From AHCA Handbook (unduplicated count within each program; hierarchical analysis; individuals are coded at the highest level of need which may encompass all lower levels of need).

³ No ALW clients with a recent evaluation.

This pattern holds true in the other counties as well. The ADI and HCE clients are also more disabled than either the ADW and ALW clients. The only exception is that in Hillsborough County the ALW clients are equally impaired as those in the ADI and HCE programs.

Nursing home eligibility is one of the requirements for receiving services through the Medicaid Waiver programs. Tables 2-6 include a hierarchical breakdown of clients in each program who meet the requirements of the program. The highest level of need (5+ ADLs) incorporates those who need some help with fewer ADLs so the remaining groups are generally smaller than the first group. For example, the percentage of individuals with a diagnosis of dementia and who require some help with 3+ ADLs is quite small in each program (even ADI). This is most likely due to the fact that these individuals require more ADL assistance and so are included in the 5+ or 4 ADLs categories. The percentages within the five eligibility categories total 100% for each program.

As expected, nursing home clients are most likely to meet the highest level of eligibility—72-80% in each county. Where this percentage is lower (e.g., Hardee County), it is likely there are fewer alternatives available and so long-term care clients are forced to use nursing home services rather than other HCBS programs. The remaining clients include those who may have a degenerative disease requiring daily nursing care (a requirement not included in the CARES or CIRT datasets and so is not possible to report) or they may not be eligible for nursing home services at all. As expected, clients in the CCE and OAA programs are represented more in this category.

Table 3
 Clients Meeting NH Eligibility Requirements by Long-Term Care Program: Highlands County

	NH	ADI	ADW	ALW	CCE	HCE	OAA
Average Number of ADLs ¹	5.09	4.47	2.70	2.10	2.14	3.43	0.99
% Living with Caregiver	4.67	100.00	39.78	50.00	45.13	87.69	16.91
% Meeting Medicaid NH Eligibility Requirements²							
Some help with 5+ ADLS	75.44	47.37	26.88	0.00	13.50	32.31	4.18
Some help with 4 ADLS + supervision of medications	11.11	26.32	5.38	20.00	8.19	12.31	2.36
Total help with 2+ ADLs	.58	0.00	2.15	0.00	.88	3.08	.73
Alzheimer's Disease diagnosis or other dementia and require some help with 3+ ADLs	3.51	10.53	2.15	0.00	5.97	9.23	1.27
Remaining clients (includes clients with degenerative disease needing nursing care)	9.36	15.79	63.44	80.00	71.46	43.08	91.45

¹ADLs include bathing, dressing, eating, transferring, toileting, and walking.

²From AHCA Handbook (unduplicated count within each program; hierarchical analysis; individuals are coded at the highest level of need which may encompass all lower levels of need).

Table 4
 Clients Meeting NH Eligibility Requirements by Long-Term Care Program: Hillsborough County

	NH	ADI	ADW	ALW	CCE	HCE	OAA
Average Number of ADLs ¹	5.11	3.73	3.17	4.07	2.28	4.09	1.39
% Living with Caregiver	15.25	95.19	51.82	4.30	43.01	98.11	36.42
% Meeting Medicaid NH Eligibility Requirements²							
Some help with 5+ ADLS	76.67	45.45	32.52	38.59	24.05	50.63	11.02
Some help with 4 ADLS + supervision of medications	10.33	12.83	4.67	25.44	4.71	9.24	3.23
Total help with 2+ ADLs	.17	.53	1.22	.88	1.88	1.68	1.20
Alzheimer's Disease diagnosis or other dementia and require some help with 3+ ADLs	2.33	6.42	2.64	18.42	1.60	3.57	1.65
Remaining clients (includes clients with degenerative disease needing nursing care)	10.50	34.76	58.94	16.66	67.77	34.87	82.90

¹ADLs include bathing, dressing, eating, transferring, toileting, and walking.

²From AHCA Handbook (unduplicated count within each program; hierarchical analysis; individuals are coded at the highest level of need which may encompass all lower levels of need).

Table 5
Clients Meeting NH Eligibility Requirements by Long-Term Care Program: Manatee County

	NH	ADI	ADW	ALW	CCE	HCE	OAA
Average Number of ADLs	5.20	4.35	2.49	3.00	1.90	3.87	1.04
% Living with Caregiver	5.18	77.08	39.72	7.24	29.75	90.57	12.85
% Meeting Medicaid NH Eligibility Requirements²							
Some help with 5+ ADLS	80.49	47.92	17.81	11.59	14.12	39.62	7.08
Some help with 4 ADLS + supervision of medications	7.01	20.83	6.84	18.84	6.41	17.92	1.98
Total help with 2+ ADLs	.61	0.00	0.00	0.00	1.16	.94	1.32
Alzheimer's Disease diagnosis or other dementia and require some help with 3+ ADLs	2.13	12.50	0.00	23.19	2.78	6.60	0.49
Remaining clients (includes clients with degenerative disease needing nursing care)	9.76	18.75	75.34	46.38	75.46	34.91	89.13

¹ ADLs include bathing, dressing, eating, transferring, toileting, and walking.

²From AHCA Handbook (unduplicated count within each program; hierarchical analysis; individuals are coded at the highest level of need which may encompass all lower levels of need).

Table 6
Clients Meeting NH Eligibility Requirements by Long-Term Care Program: Polk County

	NH	ADI	ADW	ALW	CCE	HCE	OAA
Average Number of ADLs ¹	5.34	2.42	2.57	2.90	2.44	3.86	1.23
% Living with Caregiver	9.29	84.62	36.49	9.52	41.60	88.99	19.60
% Meeting Medicaid NH Eligibility Requirements²							
Some help with 5+ ADLS	74.75	9.23	13.96	19.05	21.05	45.81	8.70
Some help with 4 ADLS + supervision of medications	11.10	16.92	4.95	14.29	7.59	12.78	1.75
Total help with 2+ ADLs	.23	0.00	4.95	0.00	3.24	2.20	1.75
Alzheimer's Disease diagnosis or other dementia and require some help with 3+ ADLs	2.60	12.31	2.25	12.70	2.94	3.52	0.61
Remaining clients (includes clients with degenerative disease needing nursing care)	11.33	61.54	73.87	53.97	65.18	35.68	87.19

¹ ADLs include bathing, dressing, eating, transferring, toileting, and walking.

²From AHCA Handbook (unduplicated count within each program; hierarchical analysis; individuals are coded at the highest level of need which may encompass all lower levels of need).

Key Informant Interviews

Information. Currently, providers have phone numbers for caregivers to call such as a helpline and crisis hotline that serve all five counties. One key informant is part of a national hotline, PKS, which is operational 24-hours a day. Providers have resources, (library of books, pamphlets, and videos), referrals, support and information, individually compiled for each caller. In Hillsborough County, providers offer a quarterly educational and informational newsletter about community services, written materials on Alzheimer's disease, resources for emergency residential placement, and offer Emergency

Alert Response Systems.

Gaining access to service system. There are many barriers to gaining access to services. Providers have criteria for eligibility for services/programs. Many services (respite, mailing, legal assistance, emergency placement) are provided through membership only. In addition, members get a \$250 reimbursement for respite care. Some respite is for emergency only. Not all groups provide respite services. There can be a fee for caregiver training, (\$20). Care receivers can be ineligible for services due to age (under 60), financial status (does not meet ICP criteria), and/or health (not diagnosed/suspected of memory loss which interferes with performing ADLs, isolated or physically, mentally and socially impaired). Priority is given to homebound low-income persons.

Support groups. Education and support groups would help caregivers to continue to provide care. Currently, providers offer evening support groups for caregivers of Alzheimer's including Spanish and teen groups by a trained volunteer. They have caregiver training that is focused on direct care while preserving the dignity and quality of life of the care recipient as well as unspecified caregiver training. Also, there is individual or family counseling related to caregiver/patient issues. There is training for Alzheimer group facilitators and information and education provided to community groups.

Respite. Of all services provided, key informants rate respite (in-home, facility-based, overnight, and weekend) the number one most requested service by caregivers. Respite would help caregivers to continue to provide care. Except for adult day care, providers offer all of these services, yet they are limited. Respite is offered for an emergency and caregivers receive financial assistance for placement and/or in-home respite care. Also, a day of respite is limited to three days per year. There is \$250 reimbursement for respite for one program. Times of services include day, evening and weekend hours. Some adult day care centers provide respite day care with activities, meals, medication management, and health monitoring. There is respite for homebound elderly by low-income trained senior volunteers.

Supplemental services. Personal care assistance is third most requested service by caregivers. Financial assistance, chore service, and meals on wheels would help caregivers to continue to provide care. Providers offer these services in addition to identifying people with Alzheimer's disease, offering legal/financial counseling, homemakers, case management, consumables/ consumable medical supplies, pest control, emergency home repair, companionship, and basic and special subsidies. Senior volunteers provide assistance with bill paying to elderly and disabled persons. There is escort and grocery shopping for homebound elderly by low-income trained senior volunteers.

Transportation. According to providers, transportation is second most requested service by caregivers. Transportation would help caregivers to continue to provide care. Currently none of the key informants offer transportation services.

Support for grandparents. Information and referral telephone service is available for grandparents raising grandchildren. There are support groups held in evening and senior volunteers that assist with bill paying. In addition there is additional respite for grandparents raising grandchildren.

Older adults caring for family members with MR/DD. No key informant mentioned offering any services for older adults caring for family members with MR/DD.

Focus Groups

There were 26 participants in four focus groups in West Central Florida counties. Of these, 10 were adult children caring for a mother or mother-in-law. One person cared for both parents. Nine cared for spouses and seven spouses caring for their husbands and two for wives. One caregiver took care of a sibling and another a friend. One participant cared for three elders and another for a stepdaughter. Ages of care receivers ranged from 60 to 95.

Care receivers were frail. Most elders had more than one medical condition. The most common medical conditions were: stroke (19), dementia/memory problems (7), heart disease (6), arthritis (6), Alzheimer's Disease (5), and Parkinson's disease (5).

Caregivers expressed that if they had a break away from caring for their frail relatives they would choose an activity in which they didn't have any demands. Thus, most activities involved doing something alone, or, if married, with their partners.

Respite services

The majority of participants expressed that they do not receive enough respite services. It was the number one priority for all focus groups. They wanted respite services for more hours on weekdays and on weekends. Caregivers indicated that respite would allow them to run personal errands, which they are not able to do on weekdays because they cannot leave their relative or because caregivers work and then come home to care for their relatives. Because this would imply leaving their relative with a stranger, caregivers expressed a desire for having someone whom they trust. Thus, the option of being able to pay a family member was appealing. As one caregiver said:

“I take care of my mother, and my brother, he is paying, he has power of attorney, but I do everything, and out of my mother's check every month, I get \$250. I don't work, because I can't, so I get nothing in. So, and I have a daughter that is 16 that's in high school that...(needs everything). But what can you pay out of \$250 when I have to pay the electricity? You know, I have to purchase the gas to cook, and I have to...”

Caregivers also mentioned the need for respite services to take a vacation. They requested having someone available to come and stay at their home. A more popular option was to receive respite services through institutions such as nursing homes and assisted living facilities, where older relatives could stay while caregivers went on a week vacation. However, those who have tried this option have been dissatisfied with the services their relatives have received. The elders have been somewhat mistreated, their preferences were not respected, or they have gotten sick due to mismanagement of their medical conditions.

“The first night she was there she asked someone to help her get ready for bed and the girl said, you can do that yourself. And mom said, no, I can’t. And she said, well, that’s what I was told and she turned around and walked out of the room...And the remainder of the weekend she had the attitude of why bother to pull the string because nobody is going to care...Then she told the lady in charge and then the lady in charge said she was going to do something about it, but then she went off with her mother to St. Augustine for the weekend, so she wasn’t there either and on top of that, you know, she’s used to being at home with me and she was down there with 50 other people. They had a virus going around. She came home she was sick for over two weeks. We had to go on antibiotics and she was just miserable.”

Cash stipend or government check

The second highest priority among focus groups was to receive a cash stipend. The majority of caregiver participants indicated that they would use this stipend to pay for respite services and for expenses not covered by other sources of support (e.g., Medicaid). That is, stipend would be used mostly to pay someone for respite services, either a professional or a relative, so they can have more hours to take care of other business (e.g., buying groceries). Among the expenses not covered by other means of support are medical expenses. Paying for medication and some medical services causes the most strain in the caregivers’ budgets. A great amount of money is being spent on buying adult diapers and linens; thus, they would use the stipend to cover these costs, too. The stipend would be spent for living expenses such as rent, electric and utility bills, or to make house modifications such as building ramps, modifying bathrooms, and installing AC and heater units (some people have these but avoid using them because of the high cost of running them), as well.

Because transportation is unreliable, some caregivers would use the stipend to pay someone to provide transportation for their elder relatives. They would either pay a taxi or another relative so the caregiver does not have to take time away from work.

Stipends would also be used to buy more quality food (e.g., Ensure) or food for special medical conditions or prescribed diets (e.g., diabetic diets). Some would like to use it simply to be able to give their relatives a treat, which they cannot afford at this time (e.g., dining at a restaurant).

Informational or “caring and sharing-type services.”

Information was the third highest priority among focus group members. Most caregivers currently use the following sources of information: family members and friends, the Internet, Department of Elder Affairs, local newspapers, churches, social workers and case managers, senior centers, support groups, or county phone numbers.

Caregivers suggested that the following sources would be the most accessible to them: newsletters, telephone information services (e.g., hotlines), guides/booklets/handbooks, newspapers, churches and hospitals. Overall, caregivers do not get timely information when they contact formal agencies. Caregivers who spoke Spanish expressed the need for receiving information in their own language.

Caregiver expressed the need to receive the following types of information:

- ***Financial information.*** Most have very few resources or have used their assets for expenses associated with caring for their relative. They believe this could have been prevented with financial advice. Further loss can still be prevented through this service. Ideally, they would like to have someone come to their home and help with financial planning.
- ***Legal information.*** Caregivers need to be informed about new regulations and elder law that would affect them. They also believe that there may be some benefits (e.g., Medicaid) to which they are entitled.
- ***General information.*** There is a need for having a referral source that can direct caregivers to agencies that would provide very concrete information and would answer their specific questions. In addition, caregivers expressed the need for receiving this information in a timely manner.

Home-based eldercare services

Caregivers currently use the following home-based eldercare services: bathing, housekeeping and homemaker, and meals-on-wheels. Caregivers would like the following home-based eldercare services: visiting nurses, grocery shopping, yard work, and outside housework (e.g., windows, roof).

Some caregivers would like to receive some of the benefits that those who are Medicaid eligible receive. Caregivers believe that sometimes they are just barely above the eligibility criteria or there may be one or two requirements that they don't meet. Thus, they suggested that eligibility criteria should be changed and work on a scaling fee for home-based eldercare services.

Caregivers believe that agencies need to have closer control of the people they send to provide services because many are unreliable or are not performing their job adequately. For example, they arrive at whatever time they want rather than when it's convenient for the caregiver. Some do not stay as long as they should or perform the work quickly without caring about quality.

A summary of key informant interviews and focus group meetings is found in Table 7. These responses are sometimes in contrast with the priorities of the Title IIIe funds and what has been found in the research to be important to caregivers.

Table 7
Summary

OAA Title III Guidelines	Research Literature/National Perspective	Provider Priorities	Caregiver Priorities
Information about services available.	Existence of services does not ensure caregivers will use them. Cultural differences in willingness to use services. Medical services do not inform families about supportive services.	Target services to Hispanic, African Americans, and caregivers of DD. Rate dementia facilities in the community.	Information was #3 on the list for focus groups. Need financial information and to know how they could have protected their own assets better. Need legal information about laws and regulations and eligibility for programs. Need concrete information about services that is provided in a timely manner.
Gaining access to service system.	Not knowing how to obtain assistance or where to call is a major barrier. Cost, availability, and accessibility, concerns about reliability, cultural traditions, and receptivity of the care receiver are often reasons for not using services. Primary barriers to obtaining services are availability, access, and cost.	CMs are burdened and cannot do the needed work and are leaving the job so there are no seasoned CMs who know what they are doing. HUD residents are falling through the cracks because not enough services. 85% of HUD residents don't meet the criteria to get services.	
Counseling and support groups, caregiver training, caregiver forums.	Caregiving affects physical or mental health (15%) and emotional health (25%) of caregivers. Caregiver strain can lead to elder abuse.	Provide brief (1 hour) caregiver training sessions with respite available. Additional support groups. Caregiver training. Training of care workers and providers.	
Respite care in home and residential settings during week and on weekends.	Average caregiver is 46 y.o. who spends 18 hours a week caregiving in addition to working full-time. 51% provide at least 1 ADL; 29% help with 3 ADLs. Increased stress related to caregiving for someone with dementia. Up to 46% are clinically depressed.	Affordable respite is #1 need identified by all key informants (in-home, facility based, overnight, weekends, and extended hours for Adult day care or Senior centers).	Respite is #1 need identified by focus groups. They need more hours, including weekends. Would prefer direct payments so they can hire a known person that they trust. They need respite in order to take a vacation (a week). Would use residential respite although some had experience with poor care. Stipends would be used to pay for respite care.

OAA Title III Guidelines	Research Literature/National Perspective	Provider Priorities	Caregiver Priorities
Supplemental services (no more than 20% of expenditures): direct services, caregiver payments, vendor payments for home improvement, chore, medical supplies and services.	Average monthly out of pocket expenditures are \$171 for caregivers of individuals with AD. Florida reports that informal caregiving is worth \$10.5 billion.	Personal care assistance is #3 need identified by key informants. Need help with personal care, chores, transportation and shopping.	Would like access to services that Medicaid clients get-they are just over the eligibility levels. Service staff is not reliable nor do they perform their jobs adequately. Stipend to pay for their own services was the #2 need of focus groups. They would use stipend for: home modifications, transportation, home expenses, food (Ensure), and adult diapers.
Transportation.		Transportation is #2 need identified by all key informants.	Transportation was not listed as a priority but was discussed as an important need related to using respite care.
Support grandparents (no more than 10% of expenditures):	Need financial support, preventive and restorative health and mental health services, child care training/parenting skills, laws and regulations about child placement, respite for working caregivers, crisis support, issues of visitation, reunification, and permanency planning; help with gaining access to services from multiple systems.	Recruit volunteers for grandparent respite support. Establish more kinship care support groups for grandparents caring for younger family members.	No focus group members were caring for a younger family member.
Older adults caring for family members with MR/DD: Information, referral, and counseling/support groups.	Critical need for respite care especially for aging parents caring for their aging children with these disabilities. Traditional aging network often denies services to these individuals.	None identified.	No focus group members were caring for someone with MR/DD.

Preliminary Recommendations

1. Increase the availability, affordability, and flexibility of respite care. Consider sliding scales so that families that do not meet eligibility requirements can make use of services. Consider direct payment of caregivers for respite so that family and friends can be used. Especially important for care receivers with dementia who would be stressed by being left with someone unknown to them (or a different caregiver every week). Allow respite for grandparent caregivers and older caregivers of adult children with MR/DD. Offer respite through congregate care facilities including ALF and NH but screen facilities for their capacity to provide dementia care.
2. Consider direct payments or vouchers to caregivers for other supportive services not readily available through other means (if not on Medicaid) including Ensure, adult diapers, other consumables, and home modifications. Make certain that the payments are adequate.
3. Develop better and more reliable information systems so that caregivers can get concrete information about financial, legal, and personal care services available to them. Regularly advertise a one stop shopping phone number (newspaper, yellow pages) so that caregivers know whom to call when there is a problem.
4. Improve transportation for participants and caregivers. Especially important for making use of off-site respite care (adult day care, senior centers) and for working caregivers.

Public Hearings

Three public hearings were organized by the Area Agency on Aging and held in Plant City, Wauchula, and Bradenton. The public hearing presented the Agency's mission and purpose, how decisions were made for budget allocations, and Year 2002 Proposed Area Plan. Preliminary recommendations for use of the Title IIIIE funds were presented as well.

The majority of the Plant City audience was made up of service providers who were concerned about the funding base for services given plans for tax and budget cuts under consideration by the Special Legislative Session. There was interest in understanding how the CCE co-payment affected the overall budget, the use of vouchers—especially for caregiver respite, and looking at Florida's tax structure. There was also interest in using non-CCE lead agency providers such as Elderlink to provide services.

Wauchula meeting participants expressed the need for better transportation services and more flexibility in the eligibility requirements for services. Disability should be more important than age and there should be a method for reimbursing caregivers while they wait to hear about Medicaid Waiver eligibility. There were several individuals who expressed a need for support of grandparents raising grandchildren.

Bradenton meeting participants directly addressed some of the preliminary recommendations for the use

of the new Title III E funds, especially the need for support groups, caregiver training, better access to information, and swifter processing of Medicaid eligibility.

Evaluation Plan

The Older Americans Act Title III E program to support family caregivers is a new initiative by the federal government to provide needed assistance to the individuals who provide 80% of long-term care to elders who need this assistance. The services that will be funded through the AAA should begin to meet the unmet needs identified by key informants, focus group members, and citizens who attended public hearings. These are also supported in the research literature. One way to ensure continuation of this funding is to evaluate the effectiveness of the additional funding which is targeted to certain services. The following program evaluation is suggested.

1. Compare program eligibility data. A comparison of data presented in Tables 2-6 for the fiscal year ending June 30, 2001 and June 30, 2002 could be conducted. It is especially important to add income eligibility data to the comparison in order to understand who well the needs of those who are of low or moderate means but not eligible for Medicaid or Medicaid Waiver services, are being served in the state general revenue funded services (CCE, HCE, ADI). This comparison will be affected by changes in funding of these programs due to budget cuts under consideration in Fall 2001
2. Compare program utilization data. A new comparison could be added to the analysis offered here that looks at program utilization of the particular services being offered as a result of Title III E funding: respite, direct payments, information and referral systems, and transportation. This comparison can look at the fiscal years ending June 30 of 2001 and 2002.
3. Follow-up focus groups with the same individuals who participated in the groups conducted for this research could be conducted in Summer 2002 to see how programs have or have not reached these individuals and met their needs.

References

- Alzheimer's Association (2000). *Alzheimer Advocacy: The future is now*. Report prepared for the Alzheimer's Association Public Policy Forum, Washington, D.C.
- Alzheimer's Association. (1998). *People, Power & Politics*. Tenth Annual Public Policy Forum Proceedings, Washington, D.C., 62.
- American Association of Retired Persons. (1995). *Grandparents as caregivers: Options for improving access to federal public benefit programs*. Washington, D.C.
- Angel, R.J. & Angel, J.L. (1997). *Who will care for us? Aging and long-term care in multi cultural America*. N.Y.: New York University Press.
- Arno, P.S., Levine, C. and Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs* 17 (2): 182-188.
- Bass, S., Kutza, E., and Torres-Gil, F. (Eds.). (1990). *Diversity in Aging*. Glenview, IL: Scott, Foresman and Company
- Baum, M. and Page, M. (1991). Caregiving and multigenerational families. *The Gerontologist*, 31 (6): 762-769.
- Boise, L. (1989). Reaching the employed caregiver. Report submitted under the Fellowship Program in Applied Gerontology, The Gerontological Society of America.
- Burnette, D. (1999). Custodial grandparents in Latino families: Patterns of service use and predictors of unmet needs. *Social Work*, 44 (1): 22-34.
- Burnette, D. (1999). Social relationships of Latino grandparent caregivers: A role theory perspective. *The Gerontologist*, 39 (1), 49-58.
- Canadian Study of Health and Aging. (1994) Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13, 470-487.
- Cantor, M.H. (1991). Family and community: Changing roles in an aging society. *The Gerontologist*, 31 (3): 337-346.
- Cantor, M. (2000). *Social care of the elderly: The effects of ethnicity, class, and culture*. N.Y.: Springer Publishing Co.
- Chalfie, D. (1994). *Going it alone: A closer look at grandparents parenting grandchildren*. Washington, D.C.: American Association of Retired Persons.

- Collins, C. & Jones, R. (1997). Emotional distress and morbidity in dementia carers: A matched comparison of husbands and wives. *International Journal of Geriatric Psychiatry*, 12: 1168-1173.
- Deimling, G. (1991/1992). Respite use and caregiver well-being in families caring for stable and declining AD patients. *Journal of Gerontological Social Work*, 18, 117-134.
- Department of Elder Affairs. (2000) Report based on a study of informal caregivers for five states. *Health Affairs*, March 1999.
- Doty, P., et al. (1998) *Comparing client-directed and agency models for providing supportive services at home: Final Report*. UCLA.
- Dressel, P.L. & Barnhill, S.K. (1994). Reframing gerontological thought and practice: The case of grandmothers with daughters in prison. *The Gerontologist*, 34 685-591.
- Family Caregiving in the U.S.: Findings from a National Survey*. (1997). The National Alliance for Caregiving and AARP.
- Fuller-Thompson, E., Minkler, M., & Driver, D. (1996, November). Parenting for a second time: Factors predictive of grandparents undertaking primary responsibility for raising their grandchildren. Paper presented at the 49th Annual Scientific Meeting of the Gerontological Society of America, Washington, D.C.
- Gallagher-Thompson, D. and Steffen, A.M. (1994). Comparative effects of cognitive-behavioral and brief psychodynamic psychotherapies for depressed family caregivers. *Journal of Consulting and Clinical Psychology*, 62 (3): 543-549.
- Haley, W.E., Clair, J.M., Saulsberry, K. (1992). Family caregiver satisfaction with medical care of their demented relatives. *Gerontologist*, 32:71-85.
- Haley, W.E., West, C.A.C., Wadley, V.G., Ford, G.R., White, F.A., Barrett, J. S., Harrell, L.E. and Roth, D.L. (1995). Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and noncaregivers. *Psychology and Aging*, 10: 540-552.
- Hinrichsen, G. and Ramirez, M. (1992). Black and White dementia caregivers: A comparison of their adaptation, adjustment and service utilization. *The Gerontologist*, 32: 375-381.
- Hirsch, C., Davies, H.D., Boatwright, F., & Ochango, G. (1993). Effects of a nursing home respite admission on veterans with advanced dementia. *The Gerontologist*, 33 (4), 523 -528.
- Hodgson, L.G. and Cutler, S.J. (1994). Caregiving and Alzheimer's disease. *Educational Gerontology*, 20 (7): 665-678.
- Hollander, M. (1999). *National evaluation of the cost-effectiveness of home care*. Health Transition Fund, Health Canada.

- Irwin, M., Hauger, R., Patterson, T., Semple, S., Ziegler, M., and Grant, I. (1997). Alzheimer caregiver stress: Basal natural killer cell activity, pituitary-adrenal cortical function, and sympathetic tone. *Annals of Behavioral Medicine*, 19: 83-90.
- Kaplan, M. (1996). *Clinical Practice with Caregivers of Dementia Patients*. Bristol, PA: Taylor & Francis, 104-105.
- King, A.C., and Brassington, G. (1997). Enhancing physical and psychological functioning in older family caregivers: The role of regular physical activity. *Annals of Behavioral Medicine*, 19: 91-100.
- Knight, B.G. and McCallum, T.J. (1998). Heart rate reactivity and depression in African American and White dementia caregivers. *Aging and Mental Health*, 2: 212-221.
- Knight, B.G., Silverstein, M., McCallum, T.J., and Fox, L.S. (2000). A sociocultural stress and coping model for mental health outcomes among African American Caregivers in Southern California. *Journal of Gerontology* 55B (3): P142-150.
- Kosloski, K. & Montgomery, R. (1993). The effects of respite on caregivers of Alzheimer's patients: One-year evaluation of the Michigan model respite program. *Journal of Applied Gerontology*, 12, 4 - 17.
- Kosloski, K. & Montgomery, R. (1995). The impact of respite use on nursing home placement. *The Gerontologist*, 35, 67 - 74.
- Lawton, M. Powell. (1996). The aging family in a multigenerational perspective. *Redefining Family Support: Innovations in Public-Private Partnerships*. Baltimore: Paul H. Brookes Co., 135-149.
- Lawton, M. Brody, E., & Saperstein, A. (1991). *Respite for caregivers of Alzheimer's patients: Research and practice*. New York: Springer.
- Lebowitz, B.D. (1985). Family caregiving in old age. *Hospital and Community Psychiatry*, 36, 457 - 458.
- Londner, R. (1992). *Growing older with a developmental disability: A double whammy?* Center on Aging and Developmental Disabilities, University of Miami, 3 (1): 1-15.
- Lugaila, T. (1998). U.S. Bureau of the Census, Current Population Reports, Series P20-506, Marital status and living arrangements: March 1997. Washington, D.C.: USFPO.
- Majerovitz, S.D. (1995). Role of family adaptability in the psychological adjustment of spouse caregivers to patients with dementia. *Psychology of Aging*, 10: 447-457.
- Metropolitan Life Insurance Company (1997). Based on a national survey of caregivers by the National Alliance for Caregiving and the American Association for Retired Persons.

- Minkler, M. (1999). Intergenerational households headed by grandparents: Contexts, realities, and implications for policy. *Journal of Aging Studies*.
- National Alliance for Caregiving and the American Association for Retired Persons. (1997). *A national survey of caregivers. Family Caregiving in the U.S.* Bethesda, MD.
- National Academy on an Aging Society. (2000). *Challenges for the 21st Century: Chronic and Disabling Conditions*, 7: 1.
- Rudin, D.J. (1994). Caregiver attitudes regarding utilization and usefulness of respite services for people with Alzheimer's disease. *Journal of Gerontological Social Work*, 23 (1-2): 85-107.
- Schultz, R., Visintainer, P., and Williamson, G. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology: Psychological Sciences*, 45: P181-P191.
- Sehm, S. D., Tully, C. T. (1994). Eldercare: The social service system's missing link? *Journal of Gerontological Social Work*, 21 (3-4): 117-132.
- Seltzer, G.B., Begun, A., Seltzer, M.M., and Krauss, M.W. (1991). The impact of siblings on adults with mental retardation and their aging mothers. *Family Relations*, 40: 310-317.
- Stone, R.I. and Hort, P.F. (1990). The competing demands of employment and informal caregiving to disabled elders. *Medical Care*, 28 (6): 513-526.
- Strawbridge, W.I., Wallhagen, M.I., Shema, S.J. & Kaplan, G.A. (1997). New burdens or more of the same? Comparing grandparent, spouse, and adult child caregivers. *The Gerontologist*, 37, 505-510.
- Teri, L., Zarit, S.H. (1991). Interventions and services for family caregivers. *Annual Review of Gerontology and Geriatrics*, 11. N.Y.: Springer, 287-310.
- United States Department of Labor. (1999). Survey conducted by the Workplace Task Force of Last Acts. *Continuing Care*, 18 (8): 2.
- Wright, L.K., Clipp, E.C. and George, L.K. (1993). Health consequences of caregiver stress. *Medicine, Exercise, Nutrition, and Health*, 2: 181-195.
- Zigman, W.B., Seltzer, G.B., Adlin, M., and Silverman, W.P. (1991). Physical, behavioral, and mental health changes associated with aging. In M.J. Janick and M.M. Seltzer (Eds.). *Aging and developmental disabilities: Challenges for the 1990's*. Washington, D.C.: American Association on Mental Retardation, Special Interest Group on Aging, 277-287