

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

Prepared for

**The Area Agency on Aging of Pasco & Pinellas, Inc.**

By

Jennifer R. Salmon, Ph.D.  
Mary Kaplan, MSW, LCSW, ACSW  
Stefanie A. Thompson, B.A.  
Glenn Mitchell, II, Ph.D.

Florida Policy Exchange Center on Aging  
University of South Florida  
USF # 30437  
Tampa, Florida 33620-3043  
Phone : 813-974-3468  
E-mail : [jsalmon@admin.usf.edu](mailto:jsalmon@admin.usf.edu)

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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 untraditional service providers, identified respite as the number one requested service program from caregivers. Caregivers need in-home, facility-based, overnight and weekend respite, and adult day care services in order to continue to provide care. Currently, providers offer these services to caregivers, yet many of the services are limited. There are volunteer and low-paid senior aides available but only for Pinellas County caregivers. Transportation was the second most important need for caregivers. Only one key informant provider offers transportation. Supplemental services are third most important need. This includes: financial assistance, chore services, meals on wheels and subsidized in-home professional caregiving to help caregivers continue to provide care. Current providers offer these supplemental services. They are planning to target underserved populations, train caregivers, increase already developed programs, expand geographic service area, increase support groups, and collaborate with other providers, such as with UPARC, Alzheimer's Family Organization, and Alzheimer's Association support groups.

***Focus Groups***

Family caregivers identified respite as their number one priority. Respite should include days, nights, and weekends in the home as well as out of the home. In addition, some caregivers would like intermittent respite rather than scheduled the same time every week. Caregiver support was the second priority. Pasco County focus groups identified personal care as important as well and Pinellas County focus groups identified paying caregivers as important. Other issues important to family caregivers included finding qualified workers, receiving accurate information on eligibility rules and services available in the community.

***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. Sponsor caregiver support groups and forums to provide skills training and mutual support networks for caregivers. Include opportunities for individual or group counseling. Help family caregivers reduce their sense of burden and when impossible to be reduced, help them to accept alternative arrangements (moving the loved one to an assisted living facility).

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. Better follow-up to be sure the services are located and used. Need to consider reasonable case management loads so that families get the support they need to do the work they do. Regularly advertise a one stop shopping phone number (newspaper, yellow pages) so that caregivers know whom to call when there is a problem.
4. 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.
5. 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.
6. Provide information and referral services to grandparents raising grandchildren. I&R should provide information about: financial assistance, health care and mental health services for grandparent and grandchildren, parenting skills training, laws and regulations regarding child placement and grandparents rights, and respite care volunteers.

## Research on Caregivers<sup>1</sup>

### *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

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<sup>1</sup> This 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 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, AAA of Pasco-Pinellas, Inc.'s 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 Pasco and Pinellas Counties and to identify both conventional and novel solutions to providing support to caregivers across the lifespan.
2. Develop a profile of clients in Pasco and Pinellas Counties in terms of level of disability, caregiver availability, and other key long-term care indicators. Using data available from CARES, CIRTS, and Medicaid, we will provide a profile of the current clients who use publicly-available long-term care services.
3. Conduct caregiver focus groups (two in Pinellas County and two in Pasco County) to get responses to the ideas in task #1 and make suggestions for ways to best support informal caregivers in the community. Focus Group members will be drawn from current clients of Pasco and Pinellas Counties and through newspaper announcements.
4. Disseminate preliminary recommendations to stakeholders, Senior Centers, press/media, etc. in preparation for Public Hearings.
5. Conduct public hearings (one in Pinellas County and one in Pasco County) to respond to preliminary recommendations. One meeting will be held in the evening to allow working caregivers to attend.
6. Develop an evaluation plan to 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.

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 65+ population in the two Counties were estimated using 2000 Census data and age-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. 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 232,052 individuals over the age of 70 in Pasco and Pinellas counties (Table 1). Using age-adjusted disability rates from the Florida oversample of the AHEAD survey, approximately 30% of this population, or a total of 70,727 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 14,145 elders will need assistance with personal care. Among those who are getting help from family (56,582), 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+			
Pasco	1912	2183	1973	1727	3109	3342	3074	3720	21,040	0.30	0.06
Pinellas	3870	4342	3970	4105	6838	7476	7343	11742	49,687	0.31	0.05

The population receiving long-term care services in Pasco County across the continuum of care is quite frail. An analysis of clients with a recent evaluation who receive long-term care in nursing homes (N=649 long-stay residents) or in one of the HCBS programs funded through Medicaid, DOEA or Older Americans Act funds (N=2,299), a large percentage need assistance with 5 or more activities of daily living (Table 2): 78% of those in nursing homes but also 51% in the ADI program, 31% of Aged and Disabled Adult Waiver (ADW), 28% in the Assisted Living for the Elderly Waiver, 28% in Community Care for the Elderly (CCE), and 51% in the Home Care for the Elderly Program (HCE). Just 8% of clients who receive Older Americans Act services have this level of need. Some clients receive services in more than one program and would be included in the percentages for each program. The need for assistance with ADLs is highly correlated with advanced stages of Alzheimer’s Disease or other dementia. Table 2 displays relatively high percentages of clients in the ADI, ALW, and HCE programs that have a diagnosis of dementia.

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

	NH	ADI	ADW	ALW	CCE	HCE	OAA
Average Number of ADLs	5.09	4.21	3.12	3.68	2.91	4.08	1.21
% with Dementia		98.57		72.73	31.37	51.67	20.17
% Living with Caregiver	24.81	92.86	44.44	4.00	44.21	96.11	19.78
<b>% Meeting Medicaid NH Eligibility Requirements<sup>1</sup></b>							
Some help with 5+ ADLS <sup>2</sup>	77.8	50.7	31.0	28.0	27.6	51.1	8.3
Some help with 4 ADLS + supervision of medications	7.7	11.4	6.0	20.0	8.1	10.6	3.3
Total help with 2+ ADLs	.9	2.9	2.3	1.4	2.7	1.7	2.8
Alzheimer's Disease diagnosis or other dementia and require some help with 3+ ADLs	3.4	10.7	1.4	18.7	3.4	.6	1.2
Remaining clients (includes clients with degenerative disease needing nursing care)	10.2	24.3	59.3	32.0	58.1	36.1	84.4

<sup>1</sup>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).

<sup>2</sup>ADLs include bathing, dressing, eating, transferring, toileting, and walking.

N=2299 clients with a recent evaluation and 724 who had a recent CARES evaluation (for nursing home and Assisted Living for the Elderly (ALW) clients).

Pinellas County clients (Table 3) are slightly less impaired in each program but show a similar pattern of impairment by program as was found in Pasco County. Two-thirds of long-stay nursing home residents need some help with 5+ ADLs but 44% of ADI and 50% of HCE clients meet this profile as well. Just 17% of ADW, 16% of CCE, 14% of ALW, and 7% of OAA clients need this level of assistance.

In both counties, clients in the two waiver programs have fewer ADLs than do the ADI and HCE programs, but clients are much less likely to have a caregiver than clients in ADI and HCE. This critical eligibility requirement for the programs is likely to be the reason clients are receiving services through the waiver programs. Based on the profiles of long-term care clients in these two counties, the programs administered by the Area Agency on Aging (ADI, ALW, CCE, HCE, and OAA) are serving individuals who would be in a nursing home if these programs were not available to keep them at home or in a homelike environment like an assisted living facility. Still, there are individuals who are in nursing homes in both counties (10% of nursing home residents in Pasco and 16% in Pinellas) that could potentially be served at home with sufficient services and support of family caregivers.

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

	NH	ADI	ADW	ALW	CCE	HCE	OAA
Average Number of ADLs	4.73	4.04	2.53	3.26	2.13	4.31	1.23
% with Dementia		100.00			31.84	56.03	26.27
% Living with Caregiver	7.21	67.98	29.60	3.12	16.44	94.40	15.91
<b>% Meeting Medicaid NH Eligibility Requirements<sup>1</sup></b>							
Some help with 5+ ADLS <sup>2</sup>	67.09	44.3	17.1	13.5	15.8	49.6	6.7
Some help with 4 ADLS + supervision of medications	11.64	19.2	6.5	24.5	6.0	15.1	4.1
Total help with 2+ ADLS	.76	3.5	2.1	.5	1.9	1.7	1.4
Alzheimer’s Disease diagnosis or other dementia and require some help with 3+ ADLS	4.39	8.4	2.1	21.9	4.4	5.6	2.2
Remaining clients (includes clients with degenerative disease needing nursing care)	16.13	24.6	72.3	39.6	71.9	28.0	85.6

<sup>1</sup>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).

<sup>2</sup>ADLs include bathing, dressing, eating, transferring, toileting, and walking.

N=5250 clients with a recent CIRTS evaluation and 2176 who had a recent CARES evaluation (for nursing home and Assisted Living for the Elderly (ALW) clients).

### ***Key Informant Interviews***

***Information.*** Currently, providers have phone numbers for caregivers to call such as a helpline and crisis hotline. One key informant is part of a national hotline, PKS, which is operational 24/7. Providers have resources, (library of books, pamphlets, and videos), referrals, support and information, individually compiled for each caller. Specifically, 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, mailed information, legal assistance, emergency placement) are provided through membership only. In addition, only 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 disqualified from services due to age (under 60), financial status (does not meet ICP criteria) and/or health (diagnosed/suspected of memory loss which interferes with performing ADLs).

***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. Currently providers offer emergency financial assistance for placement and/or in-home respite of care services as well as a day of respite, (only 3 days per year). In addition, a \$250 reimbursement for respite is offered. There are adult day care, in-home and facility based respite, and adult day health care provided by key informants. Times of services include day, evening and weekend hours. Adult day care centers provide respite day care with activities, meals, medication management, and health monitoring. Respite is provided for caregivers through the temporary placement of the patient in Hospice House or long-term care facility for up to one week. There is a respite volunteer service program. Specially, there is respite for caregivers caring for Alzheimer's patients and respite for homebound elderly by low-income trained senior volunteers.

**Supplemental services.** According to providers, financial assistance, chore services, meals-on-wheels and subsidized in-home professional caregiving would help caregivers to continue to provide care. Personal care assistance is the number three most requested service by caregivers.

Currently providers offer personal care, home nursing, day evening and weekend homemaker and companionship programs. They also offer legal assistance and financial counseling. Other programs are health support, home delivered meals, case management, identification of Alzheimer's patients, chore, emergency home repair, medical supplies, incontinent supplies, medication management, and nutrition risk reduction. In addition, consumable medical supplies, enhanced chore, environmental modification, escort, medical therapy, occupational therapy, physical therapy, speech therapy, specialized medical equipment, supplies as well as basic subsidy and money are offered. Providers offer legal and financial counseling for caregivers.

**Transportation.** Transportation is the number two most requested services by caregivers. Transportation would help caregivers to continue to provide care. Currently a few providers offer transportation services to medical appointments, community services and other destinations.

**Support for grandparents.** Information and referral telephone service for grandparents raising grandchildren is currently available, along with respite for grandparents raising grandchildren. Support groups for grandparents raising grandchildren are held in the evening.

**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***

#### ***Pasco County***

There were 13 participants in two focus groups in Pasco County. Of these, eight were adult children caring for a mother or father and seven were spouses. One person cared for a sibling and another cared for friends. Some caregivers took care of more than one person. Ages of the care receivers that were

given by participants range from 83 to 95. Participants cared for very frail elders. Most elders had more than one medical condition. The most common medical conditions were: stroke (4), dementia/memory problems: including Alzheimer's disease (6), and heart disease (3). In addition, psychological issues were mentioned, e.g. care receivers experienced grief, undiagnosed depression and behavioral problems.

**Respite (Pasco).** Caregivers expressed that breaks away from caring for frail elderly were few and far between. Most breaks involved working part-time or full-time, volunteering, being social, going to church, or on vacation with family. Other caregivers do not take breaks, only take short breaks or take breaks that are filled with worry. As two caregivers said:

“...all day and all night, or he's on the phone line. I'll tell you the best story was when I went to Europe a few years ago with a girlfriend, my phone bill was \$700.00 for one week.”

“...And I have two jobs. I have a nurse that comes in ...this is private pay...that come in three times a week for ... three hours, and then I have somebody come in on Saturdays to bathe my mother because...she's gotten incontinent and she is starting to lose her memory now.... and she's diabetic. She has a heart condition, and I have to put nitro-patches on her, and the only break I get is like maybe when I go to work. But when I have my clients, I tell them, you know, I have that phone ... in case my mother needs me, I have to leave immediately...”

Another caregiver had this to say about respite.

“Who would I go with? I've lost contact with the world, you know. This is what happens to us and we're going to have to have somebody come in and help us so we can get out and get in contact with the rest of the world.”

A few other caregivers expressed that breaks of being away from caring for their frail relatives consist of activities in which they didn't have any demands. Thus, most activities involved doing something alone, e.g. activities such as listening to music or lying down to relax.

The majority of participants expressed that they do not receive enough or any respite services. Having respite services that are flexible, e.g., during any hour and on any day, including weekends with intermittent and full time hours in addition to providing personal care was the most popular request. Further, participants want trained qualified caregivers that could be trusted. Caregivers indicated some barriers to respite services: lack of information on services, eligibility and requirements for assistance. Qualification of aides would set their minds at ease to allow for a true respite from their care duties. One caregiver said:

“...There is a lady in our park...and she said, ...‘I can do, anything, sit...or whatever, you call me. I'm willing.’ But he doesn't know her. And I don't know how his response would be to a perfect stranger coming in and saying I'm with you for the day.”

**Informational or “caring and sharing-type services (Pasco).** Some caregivers use or have used one or more of the following sources of information: friends, family, EMT workers, Alzheimer’s Family Organization, Alzheimer’s Association, CARES, support groups, Area Agency on Aging, 36-Hour a Day Book, 911 for non-emergency problems, Update from the State of Florida

Caregivers expressed the need to receive how to information that explains how to care for elders. One caregiver expressed the desire to have a person come into the home to give information one-on-one. They also want a referral source that can direct caregivers to agencies that would provide concrete information and would answer their specific questions rather than providing generalities.

Caregivers suggested that the following sources would be the most accessible to them: newsletters, telephone information services (e.g., hotlines), guides/booklets/handbooks, newspapers, one-on-one support and support groups.

In addition, some caregivers allude to sharing information with the general public thus educating them to the needs of caregivers.

“... I was born and raised in this town and my mama, everybody knows her and everybody I see, ‘How’s your mother? How’s your mother?’ They don’t ever say, how are you!”

**Home-based eldercare services (Pasco).** Caregivers currently use or have used the following providers for home-based eldercare services: CARES, (chore services and meals such as the Red Ribbon Program), Meals-on-Wheels, private pay providers, and family/friends. They need “Babysitting” services, personal care for ADLs from experienced aides who have training to understand elders with dementia, visiting nurses or someone else qualified to give medication, housekeeping, and transportation. Caregivers complained that meals are not always diet specific and providers, need to make sure they follow up in a timely manner. One caregiver has been waiting for several months to hear back from an intake worker.

**Cash stipend or government check (Pasco).** Caregivers had differing opinions regarding the cash stipend. A few already receive about \$100 a week from the Home Care for the Elderly Program and use it for personal items such as pull-ups or briefs (diapers). Other caregivers responded they would use money for chore and respite services. Further, as one caregiver said the stipend or government check would bring home her husband from a nursing home:

“Well, I could take care of him during the night...But it’s during the day...Yeah. But right now I can’t pay for anybody to come in the home with him.... You know? My husband is on Medicaid.”

The remaining caregivers did not like the idea of a cash stipend or government check and would rather see government funding for providers such as CARES or for general programs such as counseling and information.

**Three most important ways that government could assist caregivers.** Focus group participants were asked to prioritize the programs that should be considered first. Table 4 is a display of the top three priorities: respite care, support groups, and personal care.

Table 4  
Priority Services for Pasco County

Rank	General	Specific Service
1 <sup>st</sup>	Respite	Night, intermittent hours, on call hours, one full day or week respite, and part-time companions.
2 <sup>nd</sup>	Support Groups	Training and support groups, or phone calls.
3 <sup>rd</sup>	Personal Care	

### *Pinellas Focus Groups*

There were 15 participants in two focus groups in Pinellas County. Of these, 12 were adult children caring for a mother, father or mother-in-law and three were spouses caring for their husbands. One caregiver took care of more than one person. Ages of the care receivers that were given by participants range from 76 to 90. Participants cared for very frail elders. Most elders had more than one medical condition. The most common medical conditions were: stroke (4), dementia/memory including Alzheimer’s disease (3), and heart disease (3). Other conditions include diabetes, cancer, vision and/or hearing impairments, hyperglycemia, pulmonary/respiratory diseases or problems, mobility impairments and G tube. In addition, behavioral problems and psychological issues were common among care receivers, e.g. refusing to stay on special diet, anger, sadness, excessive neediness, anxiety of death, and hypochondria.

**Respite (Pinellas).** The majority of caregivers did not take breaks. Of those that mentioned taking breaks stated working, volunteering, going to school, going to a gym, sailing, taking trips, reading and making crafts. Only one caregiver responded that he does not need a break because he cares for his mother-in-law two days a week. As suggested by a participant, some caregivers only have time for a quick break:

“out for a few, just to relax, but knowing I have to hurry back because I don’t have anyone, you know, when the nurse is there.”

The majority of participants do not have respite services. Some like the idea of respite yet others suggest barriers to using respite, e.g. eligibility, finances, information, transportation, trusting the aide, qualifications, and lack of respite services at support group meetings.

Other caregivers want respite services:

“No, I haven't, (used respite) but it sounds like something I will want to get into because my mother had a lot of friends.... And one friend comes one day a week; another friend comes another day of the week. But I know that that's going to end.... So I'm kind of trying to

formulate a new game plan.”

Caregivers have different experiences using respite.

“a day care for my mother. That's given her mental stimulation. She has a little bit of dementia, but instead of sitting at home all day or me trying to entertain her, she is at a place where they have dancing and exercising...”

“... I use(d) respite down at the V.A. and my husband -- they kept him two days and called me and told me to bring him home, he was leaving. They can't have somebody that wants to leave. And then I had respite at the ...Lodge... I put him in and he was at a point where I was just almost collapsing and I made the decision to keep him in the ...Lodge after respite.” But now he is in a nursing home... permanently.”

**Informational or “caring and sharing-type services (Pinellas).** Some caregivers use or have used one or more of the following sources of information: agencies, support groups (Alzheimer’s), written material, and friends. Caregivers suggested that the following sources would be the most accessible to them: support groups/meetings, newsletters, telephone calls to caregivers home about information services, prayer chains, individual mailings, or a booklet edited by the county regarding all the services that are available. Specifically caregivers would like to have information about support groups and transportation.

“It was unbelievable. And Neighborhood Senior Services I could have never gone through all of this without it. I could never have gone through it without my Day Break with Ralph in there. The support of the group from Alzheimer's, my support group, meant everything to me.”

**Home-based eldercare services (Pinellas).** Caregivers currently use, have used or would use the following home-based eldercare services: chore services, respite in home, universal workers (i.e., aids trained to do many different tasks), occupational therapy, transportation with assistance and companionship. Specifically they mentioned weekly housecleaning and trained and screened homemakers.

Caregivers who did receive home-based eldercare services complained about the loss of chore services and unreliable, under-qualified and/or untrustworthy homemakers. In addition, some caregivers felt that providers of home-based care should allow sitters to do more than just sit. As one caregiver said:

“...they could do a little tidying up around my mother's personal things, but like I say, when they come they sit. And if they would just get up and maybe straighten up her room, you know, clean the bathroom, but they don't do anything but sit.”

**Cash stipend or government check (Pinellas).** Caregivers seemed positive about receiving cash stipends or government checks. Some would pay friends to sit with their loved one.

“... myself or my friend, I feel would have more compassion towards my mom. Than someone just coming in, just to be there for a job.”

In addition participants suggest that the money would encourage family support, yet they want it to be equitable and not means-tested.

**Three most important ways that government could assist caregivers (Pinellas).** Focus group participants were asked to prioritize the programs that should be considered first. Table 5 is a display of the top three priorities: respite care, support groups, and paying caregivers.

Table 5  
Priority Services for Pinellas County

Rank	General	Specific Service
1 <sup>st</sup>	Respite	Night, intermittent hours, on call hours, one full day or week respite, and part-time companions.
2 <sup>nd</sup>	Support Groups	Training and support groups, or phone calls.
3 <sup>rd</sup>	Paying Caregivers	

A summary of key informant interviews and focus group meetings is found in Table 6. These responses are sometimes in contrast with the priorities of the Title III E funds and what has been found in the research to be important to caregivers.

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Table 6  
Summary

<b>OAA Title III E Guidelines</b>	<b>Research Literature/National Perspective</b>	<b>Provider Priorities</b>	<b>Caregiver Priorities</b>
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 is #4 on the focus groups list. Need literature/ information about services available in Doctors' offices. Need more attention in the media on the issues surrounding caregiving. Need non-emergency phone number. Need more general recognition of problem.
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.	Expand geographical area served as well as services, specifically to Ridgecrest Community Center (African American community).	Need expanded eligibility under Medicaid.
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 caregiver education and broaden existing programs., i.e. training senior volunteers with Seniors in Service Senior Companion Program to provide home respite care to persons with dementia. Training sessions for caregivers (1 hour) with respite available. Increase support groups.	Support Services is #2 need for the caregiver. Need counseling, support and training/education. Need support groups in person as well as on the phone. Need support on different topics, e.g. emotional issues and sandwich generation. Need training/ education, e.g. on legal rules of the admission process of NH.

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<b>OAA Title III E Guidelines</b>	<b>Research Literature/National Perspective</b>	<b>Provider Priorities</b>	<b>Caregiver Priorities</b>
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.	Respite (in-home, facility based, overnight, and weekend) is #1 need identified by all key informants. Acquire a building for overnight and weekend respite, i.e. at Morton Plant-Mease, Dunedin.	Respite is #1 priority on the list of focus groups. Need evening, weekend, and intermittent and on-call hours. Need one to three full days or two to three full weeks of respite. Need part-time companions or on call sitters.
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. Provide in-home caregiver, i.e. for frail elderly caregivers needing 8+ hours of assistance per day.	# 3 need for Pasco county is personal care. Need personal care in daytime. Need chore services and housecleaning every two weeks. Need medical and nutritional supervision, with emergency phone numbers to call. Need meals -on-wheels, and food in the Senior Centers. Need range of motion therapy. Would like more church and school involvement. #3 need in Pinellas county is paying the caregiver Money would be used to choose own home health worker.
Transportation.	Not addressed in literature review.	Transportation is #2 need identified by all key informants.	Transportation was not mentioned on the lists by the focus groups, but it was mentioned as a barrier to using respite and support group services..

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<b>OAA Title III E Guidelines</b>	<b>Research Literature/National Perspective</b>	<b>Provider Priorities</b>	<b>Caregiver Priorities</b>
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.	Providers want to use kinship care support groups, recruit additional volunteers, for grandparent respite support. and expand services to grandparents raising grandchildren.	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.	Target caregivers of the developmentally disabled. Collaborate with UPARC to address the needs of developmentally disabled individuals and their aging parents.	No focus group members were caring for family members 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. Sponsor caregiver support groups and forums to provide skills training and mutual support networks for caregivers. Include opportunities for individual or group counseling. Help family caregivers reduce their sense of burden and when impossible to be reduced, help them to accept alternative arrangements (moving the loved one to an assisted living facility).
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. Better follow-up to be sure the services are located and used. Need to consider reasonable case management loads so that families get the support they need to do the work they do. Regularly advertise a one stop shopping phone number (newspaper, yellow pages) so that caregivers know whom to call when there is a problem.
4. 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.
5. 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.
6. Provide information and referral services to grandparents raising grandchildren. I&R should provide information about: financial assistance, health care and mental health services for grandparent and grandchildren, parenting skills training, laws and regulations regarding child placement and grandparents rights, and respite care volunteers.

### ***Public Hearings***

A public hearing was arranged by AAA staff in each county: Largo in Pinellas County and New Port Richey in Pasco County. Citizens and formal care providers offered public testimony or written comments on the needs of caregivers of elders and grandparents raising young grandchildren. Their comments are summarized here. The need for respite care was overwhelmingly supported by citizens at both public hearings. There was interest in off-site respite (adult day care) as well as on-site respite in

the home. In Pasco County, there was interest in vacation respite and using family and friends to provide respite care. The need for information and referral was also reinforced. Citizens wanted this information in regard to legal and financial issues, caregiver riths, support groups, and Employee Assistance Programs. Information about gaining access to AAA helpline should be posted in banks, churches, adult day care centers, and physician offices. Information and referral should be personalized and not rely on voice mail. Personal care assistance was important to citizens as well. The workers need to be reliable. Counseling and support groups were mentioned by several citizens. Support groups could be offered separately for adult children and for spouses. Facilitators need to be knowledgeable. Groups need to be offered during the day. Transportation and training of caregivers were identified by a few citizens. Several citizens expressed concern over the eligibility requirements and how they limit access to services. For example, when the care receiver is under age 60 but disabled and needs long-term care services at home.

In terms of helping grandparents caring for young grandchildren, the following services were mentioned by citizens. There is a need for information regarding community resources and legal assistance. This information should be posted in schools and children’s day care centers. Other needs included: financial assistance, transportation, respite, parenting skills training, and paying the grandparent. There was also concern about the fact that grandparents under age 60 are not eligible for the Title III E services.

### Final Title III E Allocations

The AAA of Pasco and Pinellas County proposed to allocate the Older Americans Act funding for caregiver support (Title III E) as shown in Table 4. The allocations reflect the requirements in the Act which mandate minimum and maximum amounts under each category. They types of services within each category reflect the needs of the citizens in both counties as described in this report.

Table 4  
Title III E Allocations

	<b>Pasco County</b>	<b>Pinellas County</b>
Direct Services Funding: Respite, Adult Day Care, Adult Day Health Care, Transportation, and Counseling.	123,469	257,725
Supplemental Services Funding: Chore, Medical Supplies and Services.	33,309	69,529
Grandparent Support Services: Sitter Respite, Transportation, and Legal.	11,103	23,176

### 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 and 3 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, adult day care, adult day health care, transportation, counseling, chores, and medical supplies. This comparison can look at the fiscal years ending June 30 of 2001 and 2002.
3. New programs that are not currently part of the array of services offered to elders—especially elder grandparents caring for their grandchildren—will need to be added to the utilization data: sitter respite, transportation, and legal services in regard to grandparenting concerns. These services can be included in the analysis proposed in #2 above.
4. 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.
5. Additional focus groups of grandparents could be conducted using the support groups currently underway and identified at the public hearings.

## *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*, 4:71-85.
- 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 21<sup>st</sup> 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*, Vol. 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