Family Caregiver Support:

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

November 2002

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This project was supported, in part, by a grant, number 90-CG-2567 from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

FLORIDA

Overview

Florida is a relatively large southeastern state with one of the most racially and ethnically diverse populations in the nation. The state's current long-term care system provides home and community-based services, with many programs aimed at maintaining individuals in the least restrictive environment. Florida has strong antitax sentiments, which influence new program implementation and program expansion. Despite this, an active legislature and the highest proportion of elderly residents in the nation have resulted in an abundant yet fragmented array of programs serving older persons.

Caregiver support services have been a component of many of Florida's state-funded home and community-based services. Despite previously existing respite care components and income support, passage of the National Family Caregiver Support Program (NFCSP) has allowed a significant and explicit focus on family and informal caregivers in Florida for the first time. The state's caregiver support services are characterized by:

- Centralized policymaking, with flexibility to meet the individual needs of family caregivers at the local level
- A privatized aging network and service delivery
- Many publicly funded programs that suffer from a lack of coordination and integration

Florida respondents noted that the major service needs of family caregivers are (1) respite care, (2) help with navigating the maze of services and (3) support groups and other ways to provide social and emotional support.

As Florida addresses long-term care reform and develops a statewide caregiver support program, a key consideration will be integration and coordination of the range of caregiver support services so that they are "seamless" to Florida's family caregivers.

Introduction

Florida represents an "old" state that administered programs for family and informal caregivers before enactment of the NFCSP. The project team conducted a site visit on June 3 and 4, 2002, through in-person interviews [a] with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Florida Agency for Health Care Administration

- Aged/Disabled Medicaid waiver

a All interviews except one were conducted in person. One key informant participated in one interview through phone conference.

Florida Department of Elder Affairs
- National Family Caregiver Support Program (NFCSP funded)
- Home Care for the Elderly (state funded)
- Community Care for the Elderly (state funded)
- Alzheimer's Disease Initiative (state funded)
- Respite for Elders Living in Everyday Families (state funded)
- Support Through Alzheimer's Relief System (federally and state funded)
- Aged/Disabled Medicaid waiver
- Consumer-Directed Care Project (Cash and Counseling Demonstration; federally, state and foundation funded)

Florida Department of Management Services, Americans with Disabilities (ADA) Working Group
- Real Choice Partnership Project

Stakeholders interviewed were from:
- Florida Association of Area Agencies on Aging, West Palm Beach
- Area Agency on Aging of North Florida, Tallahassee
- Alzheimer's Resource Center, Tallahassee

The seven following programs are featured in this profile:
1. Florida NFCSP
2. Home Care for the Elderly
3. Community Care for the Elderly
4. Alzheimer's Disease Initiative
5. Respite for Elders Living in Everyday Families (RELIEF)
6. Consumer-Directed Care Project
7. Aged/Disabled Medicaid waiver

Background

Florida is a large southeastern state with a population of nearly 16 million residing in 67 counties.[1] In fact, Florida is the fourth most populous state in the United States.[2]

The state has substantial low-income and minority populations. In 2000, personal income per capita was $28,145, compared to the national average of $29,676.[3] About 14.4% of Florida's population live below the federal poverty level (vs.13.3% U.S.).[4] Florida is also primarily urban, with about 93% of its population residing in metropolitan areas.[5] Florida ranks 17th nationally in percentage of households with Internet access.[6] Florida is more ethnically and racially diverse than the nation as a whole. Compared to the national average, Florida has a greater proportion of both African Americans (14.6% vs. 12.3% U.S.) and Hispanic persons (16.8% vs. 12.5% U.S.)[7] (table 1).

Florida has a large and growing elderly population. An estimated 3.6 million persons in Florida, or 22% of the state's population were 60 years or older in 2000 (vs.16.3% U.S.). Florida ranks first nationally in the number of older persons (ages 60+) residing in the state.[8] Further, the percentage of Florida's older persons increased substantially over that of the United States as a whole from 1990 to 2000 (16.3% vs. 9.4% U.S.). Unlike the state's population as a whole, Florida's proportion of

African Americans ages 60+ is slightly lower than that of the nation (6.6% vs. 8.4% U.S.). For Hispanics ages 60+, the proportion almost doubles compared to that of the United States as a whole (10.7% vs. 5.4% U.S.).[9]

Florida ranks fourth in the nation in the proportion of the population age 85 or older. In 2000, 331,287 persons, or 2.1% of Florida's population were ages 85+.[10] Despite the relatively high population of older persons in Florida, the median age of state residents is 38.7.[11] This is partly because of the large populations of college students in several of Florida's cities (e.g., Jacksonville, Tallahassee, Miami). Florida's high levels of net interstate and net international migration will account for most of the state's population growth until the year 2025.[12]

An estimated 1,472,899 family caregivers reside in Florida. These family caregivers provide about 1.4 billion hours of caregiving per year at an estimated value in 1997 of $11.2 billion.[13]

Florida's economic characteristics vary. In 1998, job growth in Florida was more than double the rate of job growth in the nation as a whole,[b] but the economic picture has changed in recent years.[14] The Medicaid program has experienced significant shortfalls, to the tune of $1.5 billion during the 2001 legislative session. [15] Growth in enrollment, home and community-based services and health care costs are cited as reasons for the shortfalls.[16] Florida ranks 42nd in terms of state/local tax burden for residents, probably because there is no state personal income tax.[17]

b Projected job growth for Florida was 2.9% in FY 1997–98 compared to 1.3% for the nation.

Table 1. Selected Characteristics of FLORIDA and the UNITED STATES, 2000 [a]

	Florida	United States
Total Population Characteristics		
Total Pop.[b]	15,982,378	281,421,906
% African American[c]	14.6%	12.3%
% Hispanic [d]	16.8%	12.5%
Older Population Characteristics		
Pop. 60+[e]	3,545,093	45,797,200
% 60+[f]	22.2%	16.3%
National ranking 60+ [g]	1	NA
Pop. 65+[h]	2,807,597	34,991,753
% 65+[i]	17.6%	12.4%
National ranking 65+ [j]	1	NA
Pop. 85+[k]	331,287	4,239,587
% 85+[l]	2.1%	1.5%
National ranking 85+[m]	4	NA
% increase 1990–2000 60+ pop.[n]	16.3%	9.4%
% White (60+)[o]	81.2%	82.4%
% African American (60+)	6.6%	8.4%
% Hispanic (60+)	10.7%	5.4%
% Asian (60+)	0.7%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics [p]		
# of caregivers (1997)	1,472,899	25,798,370
Caregiving hours (millions) (1997)	1,371.0	24,013.1
Value of caregiving (millions) (1997)	$11,214.6	$196,426.7
Economic Characteristics		
Per capita income [q]	$28,145	$29,676
% of pop. below poverty (1997)[r]	14.4%	13.3%
Internet		
% of households w/Internet access (2001)[s]	43.2%	41.5%
Nat'l ranking of households w/Internet access	17	NA

a Unless otherwise noted, all data are from 2000.
b MapStats-Florida, www.fedstats.gov (June 2002).
c Ibid.
d Ibid.

e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.*
f Ibid.
g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.*
h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
i Ibid.
j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States.*
k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
l Ibid.
m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States.*
n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data, www.aoa.gov/Census 2000/stateprofiles/ageprofile-states.html.*
o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islander and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000, www.aoa.gov/stats/2000pop/percent60plusxrace-HO.html.*
p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
r MapStats-Florida.
s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002, www.governing.com/source.htm.* Source for Internet access is the National Telecommunications and Information Administration, 2001.

State Administrative Structure

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies: the Department of Elder Affairs (DOEA) and the Agency for Health Care Administration (AHCA). The AHCA develops and carries out policies related to the Medicaid program. The programs administered by these state agencies rely on federal funds along with significant state general funds. Particularly in the growth years in the early and mid-1990s, Florida legislated many programs to serve the elderly and persons with disabilities. Key informants cited the legislature as the impetus for the enactment of many existing programs.

The DOEA is a freestanding department, serving as the State Unit on Aging and administering the provisions of the federal Older Americans Act, including the new NFCSP. In addition, the DOEA administers the following programs that serve older persons and their family caregivers: Community Care for the Elderly, Alzheimer's Disease Initiative, Home Care for the Elderly, Respite for Elders Living in Everyday Families (RELIEF), Consumer-Directed Care Project and Support Through Alzheimer's Relief Systems (STARS). The governor appoints the secretary of the department. The DOEA, under an interagency agreement with the Florida AHCA, also administers the Assisted Living for the Elderly and Aged/Disabled Medicaid waivers.[18]

The infrastructure of Florida's aging network is a statewide system of 11 Area Agencies on Aging (AAAs), private, nonprofit agencies that cover geographic regions ranging from one to 15 counties. Each AAA has at least one Medicaid waiver specialist to enroll and monitor provider operations. DOEA staff, using the Comprehensive Assessment and Review and Evaluation Services (CARES) evaluation instrument, determines functional eligibility for Medicaid waiver services. Each Planning and Service Area (PSA) has CARES staff who are sometimes colocated with the AAA.[19] Most of the other programs serving older persons are run through the AAAs, which subcontract with service providers for these non-Medicaid services.

Florida's Aged/Disabled Medicaid waiver was originally approved in 1982. The Florida AHCA is responsible as the "single state agency" for oversight of Medicaid. The Agency sets program policy and the DOEA operates the Medicaid waiver program serving about 13,335 beneficiaries in the state (29,736 total slots).[c]

Florida was also awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services in 2002. Referred to as the Real Choice Partnership Project, it is administratively housed within the Department of Management Services and falls under the Americans with Disabilities (ADA) Working Group, which was created by Executive Order. The ADA Working Group, which serves primarily the developmental disability community, was placed in the Department of Management Services because its work cuts across so many departments. The Real Choice grant will create a Clearinghouse on Disability and develop three pilot sites to improve the structure to deliver services. It will include cross-cultural, cross-age coalition building. Ultimately, the mission of the grant is to eliminate current barriers to offering services in the least restrictive setting. The ADA Working Group considers itself the *Olmstead* Task Force, although not all key informants identified it as such.

Overview of State System of Caregiver Support

Florida has historically invested state general funds in developing services for older persons. Increasingly, however, there has been an emphasis on moving older persons from state-only–funded programs to programs that receive federal matching funds, such as the Medicaid home and community-based care waivers. The state's growing fiscal conservatism may be due to the political shift in the executive and legislative branches of government in 1998, with Republican Jeb Bush taking the gubernatorial lead and with republican majorities in the Florida House and Senate.[20]

Florida's current long-term care system has developed in a fragmented way, with many programs beginning as the result of legislation, rather than from a systems development perspective. Recently, however, Florida enacted legislation, S.B. 1276, establishing the Office of Long-Term Care Policy to create a more integrated, streamlined approach to policy development and program administration.

Many of Florida's programs providing caregiver support predate the passage of the NFCSP under the Older Americans Act Amendments of 2000. Programs assisting caregivers are housed in two DOEA divisions: Statewide Community Based Services and Volunteer and Community Services. The Division of Volunteer and Community Services provides education, intervention, and prevention services and develops and enhances community supports for elders, their families and caregivers.

c Florida has 11 Medicaid Home and Community-Based Services waivers. They include the Aged/Disabled waiver implemented in 1982; Developmental Services waiver implemented in 1985; Channeling waiver implemented in 1985; Project AIDS Care implemented in 1989; Model waiver implemented in 1991 (serving only five clients); Assisted Living for the Elderly implemented in 1995; Supportive Living implemented in 1995; Nursing Home Diversion implemented in 1997; Family Planning implemented in 1998; Traumatic Brain Injury/Spinal Cord Injury waiver implemented in 1999; and Consumer Directed Care demo (Cash and Counseling Demonstration project) implemented in 2000.

Family and informal caregivers are explicitly recognized as a central component of the current long-term care system. A DOEA official indicated that the recognition was partially because of the increase in resources for caregiver programs on the state level. One stakeholder said that explicit recognition in state statute was only in the Home Care for the Elderly program, however. Medicaid officials stated that recognition is not formal; but rather provided through the development of home and community-based waiver services. Although many Florida programs do provide caregiver support services, (e.g., respite care), no state-funded program has specifically targeted family and informal caregivers. Programs such as Home Care for the Elderly provide a limited financial subsidy and RELIEF provides respite and other limited informal supports. These programs are not as comprehensive as the NFCSP.

Florida is one of three states chosen to participate in the national demonstration project known as Cash and Counseling.[d] At the state level, the program is referred to as the Consumer-Directed Care Project and is administered by the DOEA. The national program is a partnership among the CMS, the U.S. Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE) and The Robert Wood Johnson Foundation. Florida also contributes state general funds to the program. The program is implemented under an 1115 Medicaid waiver and was initiated to research issues and questions about Medicaid recipients managing their own care. Enrollees can hire and direct employees of their choosing, including family and friends. The waiver allows for enrollment of 6,000 Florida residents meeting functional criteria and already enrolled in Florida's Medicaid waivers. Populations include frail elderly, adults with physical and developmental disabilities and children with developmental disabilities. As of August 1, 2002, almost 3,000 people were enrolled in the demonstration project. The state's inclination to develop programs serving older persons includes the enactment of a state consumer-directed care project building on its demonstration project. The state project is administered by the AHCA, as opposed to the DOEA. The enactment was part of S.B. 1276.

Although the DOEA administers a variety of programs serving older persons, the system is not seamless to the consumer. Duplicative and often fragmented services may challenge consumers to understand and make sense of Florida's system of care. This is confounded by the fact that not all programs provide services statewide, such as the STARS program, available in five of Florida's 11 AAAs. Said one stakeholder, "[It's] a nightmare to get services. Programs are split up among so many different departments. Families have to go to so many places to get help." While Florida is primarily urban, one stakeholder indicated that serving rural populations is still challenging, particularly because of the workforce shortage. This means that even if services are available, providers may not be. One solution Florida has begun to implement is the expansion of the Consumer-Directed Care Project to serve more people than in the federal demonstration project. Another promising direction is the recent establishment of the Office of Long-Term Care Policy to address fragmentation and integration issues.

d The other two states chosen to participate are Arkansas and New Jersey.

Program Background/Development [e]

The original impetus for Florida's family caregiver support program was passage of the Older Americans Act Amendments in 2000, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. While the NFCSP is the only program administered by the DOEA that specifically targets services to caregivers, other programs do provide some measure of caregiver support. These include the Home Care for the Elderly program, established in 1977, which provides caregivers with a "no strings attached" subsidy up to $106 per month. DOEA surveys indicate that the funds are most often used for food (32%), medical supplies (23%) and household bills (15%). Only 3% of caregivers served use the subsidy for respite.[21]

Key informants observed that Florida is still in the start-up phase of the NFCSP. Programs and services were phased in, with AAAs contracting for services beginning in October 2001. The DOEA began in the start-up and development phase by developing guidelines, stating that it worked with AAA staff and learned what the AAAs wanted to do with the program. State officials indicated that a joint meeting in November 2001 with AAA directors was the impetus for starting an NFCSP work group to achieve consensus on a variety of program issues.

The DOEA has given AAAs flexibility to design programs that best meet local needs, although one key informant said that "the flexibility has thrown us off.…We are just beginning to appreciate it and it is increasing creativity." Further, a respondent indicated that "as long as you are doing good, it's okay." State officials have said that they would like to see more uniformity across the state but have indicated that this would be problematic because local planning groups have varying interests.

Most rewarding: Key informants noted that the most rewarding aspect of the program's development has been the significant influx of funding truly devoted to caregiver needs and to helping struggling families. Further, one respondent commented that the focus is upon providing relief to caregivers, saying, "To maintain the individual in the community…to have caregivers and support them is key."

Biggest challenge: According to key informants, one of the biggest challenges in developing the program has been to properly interpret the program guidelines of the U.S. Administration on Aging (AoA). Also cited is the challenge of developing a baseline for expectations.

Funding

In FY 2001—the first year of federal funding under the NFCSP—Florida's NFCSP received $8.7 million in federal funds, or slightly more than 3%[f] of the overall DOEA budget.[22] In FY 2002, the federal share of NFCSP funds was increased, with Florida receiving a total of about $10 million. By comparison, in FY 2001, the total cost of services under the Aged/Disabled Medicaid waiver in Florida was $82.2 million, serving about 13,000 people, including some 12,000 older persons. Of

e Additional background information on Florida's programs serving family and informal caregivers can be found in *Survey of Fifteen States: Caregiver Support Programs: Final Report* (San Francisco: Family Caregiver Alliance, October 1999).

f DOEA's FY 2002 appropriation is $305.5 million, which includes $72 million in federal funds for the Aged/Disabled Medicaid waiver.

this amount, approximately $8.2 million went for respite care. The annual per capita cost under the Aged/Disabled waiver was $7,656. Expenditures for the Aged/Disabled waiver represent about 3% of AHCA's expenditures under the Medicaid program.

Florida has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid and to support home and community-based care. Funds have not been appropriated specifically for caregiver support services, however. In FY 2002, Florida received $731 million in tobacco settlement revenues and carried over approximately $100 million in unspent funds from the prior fiscal year.[23] Of those funds, the DOEA received $25 million, with $3 million earmarked for assisted living and home and community-based care.[24] Medicaid programs received $68 million.[25] Most of the tobacco funds, however, went to the Lawton Chiles Endowment Fund for Children and the Elderly. Of the $200 million given to the trust fund, $25.1 million were allocated for the DOEA to fund programs such as osteoporosis screenings.[26]

Key informants said that the budget situation is not as bad in Florida as in other states and ascribed this to conservative steps taken early on by the legislature. Indeed, the Florida legislature has called three sessions to address state budget issues. Despite staff cuts at the DOEA, services have not been affected, and respondents indicated that the legislature is making a real commitment to the aging network. Medicaid officials portrayed a somewhat rosier picture in Florida than in other states. They indicated that the Aged/Disabled Medicaid waiver had not been significantly affected because of some surpluses and because of interest in moving people from state-funded programs into Medicaid waiver programs.

Program Administration

The DOEA sees its role in developing and implementing the state's first explicit caregiver support program as being in the areas of oversight, design, implementation, policy development, evaluation and quality control. In the words of DOEA respondents, "We monitor and survey consumers directly." State officials indicated that they also play an indirect role in developing state legislation by providing information, perspective and policy development. Policy development and program administration are centralized at the state level.

State officials emphasized the role that AAAs play in serving Florida's older persons, since 94% of the DOEA's funding is through services delivered by private nonprofits, either by the AAAs or through subcontractors. Further, DOEA expects the AAAs to develop local policy, while the DOEA provides the broad guidelines for this effort. Respondents indicated that one reason for the emphasis on flexibility to meet local needs is that demographics vary widely across the state. The median age for the entire state is 38.7 years,[27] with a median age of 54.3 in Charlotte County [28] but of 29.1[29] in Alachua County, where the University of Florida is located.

While the DOEA publicizes the NFCSP in its newsletter, "Elder Update," and has sponsored a state Caregiver Forum, AAAs are responsible for the majority of publicity efforts. Some AAAs, such as the Area Agency on Aging of North Florida, have focused resources on billboard and radio advertising.

State Medicaid officials indicated that their role is to make sure that programs operate appropriately; they said they had "no other direct role."

Program Eligibility/Assessment Process

Eligibility for Florida's family caregiver support program is consistent with federal requirements under the Older Americans Act: the program is open to family or informal caregivers of any age who provide care to persons 60 years or older, as well as caregivers age 60 or older who are caring for children age 18 or younger.[g] For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or two instrumental activities of daily living (IADLs). The family caregiver is considered the client in the program.

Client assessment standards are uniform across the state. For the NFCSP, the assessment is usually completed by a "lead agency," subcontracted by an AAA to assess clients for most of their programs. State officials noted that the assessment tool, known as the 701B, focuses on both the caregiver and the care recipient, although respondents characterized the caregiver section as informal. The 701B is used for all of Florida's home and community-based services for the elderly.

Caregiver questions include:

- How is your own health?
- How long have you been providing care?
- How likely is it that you will continue to provide care?
- Since you began providing care, have various aspects of your life become better, stayed the same or worsened?

Informal care is taken into account in the authorization of paid services for the care recipient, with DOEA officials indicating that the assessor looks at what services are being provided by family and friends. All assessments are done in home. Consumers are reassessed annually if they are receiving "hard" services, such as respite care, whereas reassessment can vary, if it takes place at all, for recipients of "soft" services (e.g., information, assistance, support groups).

Eligibility for the Aged/Disabled Medicaid waiver program is consistent with federal requirements regarding functional eligibility: enrollees must meet medical criteria for Medicaid nursing home level of care. The assessment is conducted by CARES staff. Financially, waiver participants must have income at 90% or less of the federal poverty level and meet Florida's asset limit ($2,000 for an individual, $3,000 for a couple). Recently, the state "also reduced income eligibility thresholds for the state's elderly and disabled Medicaid expansion program, causing an additional 1,500 beneficiaries to lose coverage."[30]

Respondents noted that the care recipient is the identified client in the Medicaid waiver program but said that the mind-set is to take the family caregiver into account. Consistent with Medicaid policy generally, respondents noted that the extent of informal care (i.e., whether or not the care recipient has a family caregiver) is taken into account in the authorization of paid services for the care recipient. This means services may be reduced for a care recipient with an available family caregiver.

g This includes caregivers 60+ who are caring for children affected with mental retardation or who have developmental disabilities.

Services

Although some of Florida's AAAs may provide services in all five NFCSP service categories, all services may not be available in each county even within an AAA's PSA. One rationale offered for the variability is the interest not to duplicate services. Because some of Florida's other home and community-based service programs also vary by county, services may be otherwise available in some parts of a PSA and unavailable elsewhere.

AAAs have the option to provide direct services to family caregivers, and many do, offering such services as counseling, training (professional and nonprofessional), organization of caregiver forums and family consultation. Each AAA has a staff person to assist in local coordination of the NFCSP and may provide some of these services.

Under the NFCSP, there is no cap for respite services, although individual AAAs may impose one if they choose. Informally, $999 is referred to as a possible level of capped respite, but state officials indicated that this is not a formal cap and that the issue is not about caps but about encouraging the caregiver to get out of the home to receive respite in the first place. In-home, adult day services and overnight and weekend respite are all allowed under state guidelines, although worker shortages and budgets may affect the availability of overnight and weekend respite. Respondents said that waiting lists do exist for respite and indicated that they are because of NFCSP funding shortages.

Under the Aged/Disabled Medicaid waiver, respite services, education and family training are the only services specifically provided for family caregivers. Under the Aged/Disabled waiver, there is no stated respite service cap, but the respite must be of a "short-term nature."[h] Covered respite services include in-home respite assistance, adult day health services, overnight facility-based respite and weekend respite. Respite camps are not specifically prohibited, but approval for this service would be based on the qualifications of providers, according to state Medicaid officials. Waiting lists, referred to as "assessed priority consumer lists" exist for some Medicaid waivers; respondents indicated that network capacity is the primary reason for the wait. Consumers on the list are ranked on a scale of 1 to 5. Staff indicated that they are now serving the 2s on the list, with a total priority list of about 2,000 consumers.

Major services needed by caregivers: At the DOEA, respite care, support groups, help with navigating the maze of social services and technology (e.g., home kits for surveillance and distance communication for caregivers who are far away) were identified as the major services needed by family caregivers. Respondents indicated that caregivers also needed something that would allow them to take the respite. This could be transportation to get somewhere or, respondents said, a place to go. Medicaid waiver staff and some stakeholders also indicated that respite is the major service needed by caregivers. Stakeholders pointed out the importance of breaking the mold of "in-home, alone" respite and that adult day care services provide socialization for the care recipient and give the caregiver a real break. Respite outside of the traditional eight-to-five workday, as well as service coordination and in-home counseling, were also cited by stakeholders as services needed by caregivers.

h Florida's Channeling waiver caps respite at 14 days per fiscal year. State officials said that a caregiver who needs more relief than this is in danger of caregiver "burnout," which could then cause the care recipient to deteriorate. They indicated that a request for excessive respite is considered to be a sentinel event.

Table 2. Family Caregiver Support Services in Florida

Program	Florida NFCSP	Home Care for the Elderly	Community Care for the Elderly	Alzheimer's Disease Initiative	Respite for Elders Living in Everyday Families (RELIEF)	Consumer-Directed Care Project	Aged/ Disabled Medicaid Waiver
State Administrative Responsibility	DOEA	DOEA	DOEA	DOEA	DOEA	DOEA [a]	DOEA [b]
Local Service Delivery	AAAs [c]	AAAs	Lead agencies [d]	AAAs	NA (with assistance, consumer chooses service providers)	AAAs Direct local service provider agencies [e]	AAAs
Funding Source	Older Americans Act, Title III-E	State general funds	State general funds Tobacco settlement funds	State general funds	State general funds	Medicaid 1915 (c) waiver Robert Wood Johnson Foundation State general funds	Medicaid 1915 (c) waiver
Expenditures FY 2001–02	$10 million	$9.5 million	$42.4 million	$12.2 million [f]	$1.3 million	$1.5 million [g]	$82.2 million Approximately $8.2 million for respite care [h]

a The DOEA has administrative responsibility for the Cash and Counseling Demonstration project (known as Consumer-Directed Care Project), but the AHCA has administrative responsibility for the state-enacted component of the Consumer-Directed Care Project.
b AHCA sets program policy for the Aged/Disabled Medicaid waiver.
c AAAs = Area Agencies on Aging.
d Lead agencies are composed of 42 nonprofit organizations and 10 county/local government agencies.
e RELIEF is available in 12 Florida counties.
f Expenditures represent funding for all components of the program: respite care, memory disorder clinics/model day care and brain bank. Respite was funded at $7.8 million for FY 2001–02 and served 3,890 clients (excluding clients who received only model day care services).
g Expenditures are for FY 2000–01 and represent combined federal, state and foundation funding.
h Respite share represents figures from FY 2000–01.

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

Program	Florida NFCSP	Home Care for the Elderly	Community Care for the Elderly	Alzheimer's Disease Initiative	Respite for Elders Living in Everyday Families (RELIEF)	Consumer-Directed Care Project	Aged/ Disabled Medicaid Waiver
Client Population	Family & informal caregiver	Elderly 60+ in family living situation	Care recipient family caregiver	Care recipient family caregiver	Full-time caregiver of frail, homebound elderly	Frail, elderly, adults w/ physical disabilities, adults and children w/ develop-mental disabilities	Care recipient
Eligibility Criteria:							
Age	60+ care recipient Family caregivers of any age of persons 60+	60+ care recipient	60+ care recipient	18+ care recipient	60+ care recipient	variable	18+ care recipient
Monthly Income	None	$1,536	Sliding scale co-payment	Optional sliding scale co-payment	None	$1,536	$1,536
Assets	None	$2,000	None	None	None	$2,000	$2,000
Functional Ability	For respite and supple-mental services, care recipient must have at least 2 ADLs or IADL needs	Nursing home level of care; adult caregiver providing care or to locate care	Functional impairment[i]	Diagnosis of Alzheimer's or other memory disorder	Frail elderly	Nursing home level of care; must be able to direct own care	Nursing home level of care for care recipient
Uniform, Statewide Caregiver Assessment	Yes	Yes	Yes	Yes	Yes	No	No

i Florida's *Resourge Manual* also indicates that, per statute, "primary consideration for services is given to elderly persons who are referred and determined by adult protective services to be victims of abuse, neglect, or exploitation who are in need of immediate services to prevent further harm."

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

Program	Florida NFCSP	Home Care for the Elderly	Community Care for the Elderly	Alzheimer's Disease Initiative	Respite for Elders Living in Everyday Families (RELIEF)	Consumer-Directed Care Project	Aged/ Disabled Medicaid Waiver
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	$106 cash subsidy per month	Respite (adult day health and other)	Respite Training "Other support services"	Respite	Menu of services needed as determined by care recipient	Respite Family training Education Support
Respite Cap	Varies by AAA	NA	Varies by AAA	Varies by AAA	4 hours/week	Level of respite needed determined by care recipient	No stated cap; respite must be of "a short-term nature"
Consumer Direction	Yes	Yes [j]	No	No	No [k]	Yes	No
Family Caregivers Paid as Respite Providers	Yes	No	No	No	No	Yes	No

j In addition to the basic subsidy, special subsidies may be authorized for some consumers to be used for services that help maintain individuals at home.

k Services are provided by trained volunteers, including but not limited to AmeriCorps and Senior Companion volunteers. Some participants may receive stipends.

Consumer Direction

The state has built consumer direction into the NFCSP program so that all consumers have the option of paying family and informal caregivers to provide respite and personal care. Respondents indicated that reimbursement for personal care is not specified, but is simply allowed as a component of respite care, however. Respondents stated that the idea of "getting consumers involved in determining their own destiny" had influenced the incorporation of consumer direction into the NFCSP.

The traditional Aged/Disabled Medicaid waiver does not provide for consumer direction. Medicaid officials said that the consumer-directed care projects (federal Cash and Counseling Demonstration and the recently enacted state-passed consumer-directed care project) serve that purpose.

Quality Assurance and Evaluation

The state has developed a uniform client enrollment and tracking procedure for the DOEA's programs and services. Although the system is uniform, however, certain data elements are specific to each program, so that Community Care for the Elderly may not require the same information as Older Americans Act programs. The database is called Client Information Registration Tracking System (CIRTS). Once data is collected, it is "batch entered."

The DOEA is still in the process of determining all of the information to be captured under CIRTS for the NFCSP. Staff indicated that they have set up a work group with the AAAs to decide what data should be captured. Further, respondents noted that AAAs felt that the DOEA was exceeding its authority with its proposed requirements. As of the June 2002 site visit, this issue had not been resolved.

In many of the programs serving older persons, Florida is under legislative mandate to measure outcomes. Key informants did not expect this practice to change for the state-run NFCSP.

Under the Aged/Disabled Medicaid waiver, respondents indicated that some data are collected about caregivers—but specifics were not offered. Medicaid staff did note that the Channeling waiver may collect more caregiver information because a stronger case management focus increases the interaction between the case manager and the caregiver.

Systems Development

Respondents indicated that they are still in the early stages of implementing the NFCSP and that it was too soon to describe their experience with the program. Key informants did state, however, that Florida was "ahead of the curve" in terms of supporting caregivers, considering the variety of programs serving older persons and their caregivers.

State officials have identified the Office of Long-Term Care Policy as the entity charged with coordination of family caregiver support services across state departments. This office was created in S.B. 1276 in the 2002 legislative session and will be housed in the DOEA. S.B. 1276 also instructs the DOEA and AHCA to determine ways "to transition all state-funded services" for older persons into, "a managed, integrated LTC delivery system under the direction of a single entity."[31]

Caregiver services are coordinated at the local level by the AAAs, who have responsibility for coordinating most all services and ensuring that services are seamless to consumers. Stakeholders have

commented, however, that services are coordinated within programs but not across programs. At the state level, services are coordinated at the DOEA, through monitoring of AAA services, review of AAA area plans and development of Florida's State Plan on Aging.

Respondents said that the NFCSP is integrated into the state's other long-term care programs, although some indicated that tension between local and state efforts has challenged efforts to fully integrate services.

State Involvement of Family Caregivers in *Olmstead* Decision Planning

Florida has been relatively active in response to the U.S. Supreme Court's *Olmstead* decision. Activities include a state expansion on the federal Ticket to Work legislation, which allows disabled individuals to return to work while still retaining Medicaid coverage. The federal bill caps income eligibility at 90% of poverty level, or $7,740. Florida's program is much more expansive, however, capping eligibility at 250% of poverty level, or $21,475. The state's two Systems Change grants have also focused on integrated service delivery and enhancement of home and community-based services for the disabled.

Although it is not officially designated as such, the ADA Working Group acts as the state's *Olmstead* task force. In addition, Florida had a blue ribbon committee on long-term care that has since disbanded. The committee held public forums, but although caregivers had the opportunity to be involved, one key informant indicated that no special effort had been made to ensure their participation.

Other Policy Issues

State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, responses were mixed. Medicaid officials and some DOEA respondents agreed that the priority was "medium," whereas another DOEA official indicated a "high" priority. Two stakeholders cited a "low" priority, and one stakeholder stated that the priority was "high."

Number of Key Informants	Priority on Caregiver Support
2	→ Low
2	→→→ Medium
2	→→→→→ High

Benefits and challenges: Florida case study respondents identified four aspects of their program that are most beneficial to family caregivers:

1. Respite care—to free up a family, providing caregivers with the opportunity to enjoy something "other than being tied down" to their responsibilities

2. Availability of in-home services—so caregivers do not have to "carry the client all over creation"
3. Nonmedical services (such as personal care and chore services)—to free up the caregiver to do other things
4. Waiver services—to provide the family with an alternative to placing the care recipient in a nursing home

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

- Obtaining funding—particularly convincing legislators that programs need priority and cost-containment measures
- Standardizing programs and services using the current model of decentralized, privatized service delivery
- Coordinating and collaborating with stakeholders to achieve consensus
- Garnering public support and acceptance of new programs, particularly given Florida's strong antitax sentiments
- Working with communities that are not accepting of human service programs—e.g., with communities in which a stigma is associated with certain types of care, such as nursing homes, so that families may place a care recipient in an assisted living facility to avoid that stigma even if it is not clinically the most appropriate setting

Major lesson learned: Key informants identified two major lessons learned in providing caregiver support services:

- Programs that have to cut services face great challenges. One respondent offered the example of the Home Care for the Elderly program when the DOEA suggested that the $106 monthly subsidy would have to end as recipients transitioned to Medicaid services. There was a "painful uproar" from clients. Yet as one state official observed, this small cash subsidy program is the "most effective of all our programs in terms of nursing home diversion."
- Greater flexibility in meeting the needs of family caregivers is better for the caregiver and the care recipient.

Opportunity for expanding caregiver support: Respondents indicated that Florida's future is unclear as it pertains to expanding caregiver support services. Although some thought it likely that the state would expand community options and consumer-directed care, others based program expansion on the success of transferring clients from programs funded exclusively with state dollars to Medicaid.

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

- Do not take the "cookie cutter" approach to program design.
- Develop systems more.
- Build partnerships and develop collaborations at the local level, in the beginning phases of program development.

Notes

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30 A. Yemane and I. Hill, *Health Policy for Low-Income People.*
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