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

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ALABAMA

OVERVIEW

Alabama is a southern state with substantial rural, low-income and minority populations. The state's current long-term care system provides minimal home and community-based care services, constrained by low state revenues and a strong nursing home lobby, although efforts are being made to expand home and community-based care. State-only-funded programs for the elderly and for persons with disabilities are extremely limited because of the state's antitax sentiments.

State policy attention to caregiver support services emerged only recently, with the passage of the National Family Caregiver Support Program (NFCSP) and the infusion of federal funds into Alabama's state budget. The state's developing caregiver support services are characterized by:

- ◇ Centralized policymaking and administration with statewide policies and standards to ensure a consistent approach to caregiver support
- ◇ A statewide logo and name, *Alabama Cares*, to promote a consistent, statewide identity for the program
- ◇ Flexibility to meet the individual needs of family caregivers at the local level

Alabama respondents noted that the major service needs of family caregivers are (1) supplemental services (e.g., consumable supplies, home modification), (2) respite care and education about the need for respite and (3) skills training.

As Alabama continues to develop its caregiver support program, a key consideration will be the coordination between *Alabama Cares* and the broader long-term care system, particularly through the Aged/Disabled Medicaid waiver.

INTRODUCTION

Alabama represents a "new" state that is providing caregiver support for the first time as a result of the passage of the National Family Caregiver Support Program (NFCSP). The project team conducted a site visit on March 18 and 19, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

- ◇ Alabama Department of Senior Services
 - ◆ *Alabama Cares* (NFCSP funded)
 - ◆ Aged/Disabled Medicaid waiver
 - ◆ Federal Alzheimer's disease Demonstration Grant to States

- ◇ Alabama Department of Public Health
 - ◆ Aged/Disabled Medicaid waiver

- ◇ Alabama Medicaid Agency, Long-Term Care Division
 - ◆ Aged/Disabled Medicaid waiver
 - ◆ Real Choice Systems Change grant

Stakeholders interviewed were from:

- ◇ Alabama Association of Area Agencies on Aging
- ◇ Alzheimer's Resource Center, Dothan, Alabama

Two programs are featured:

1. *Alabama Cares*
2. Aged/Disabled Medicaid waiver

BACKGROUND

Alabama is a southern state with a population of 4.5 million residing in 67 counties.¹ Most of the residents are native to the state, with 76% of the citizens born in Alabama.²

The state has substantial rural, low-income and minority populations. Nearly one-third of Alabama's population lives in rural areas.³ In 2000, personal income per capita was \$23,471, compared to the national average of \$29,676.⁴ About 16.2% of Alabama's residents live below the federal poverty level (vs. 13.3% U.S.).⁵ Alabama ranks 43rd nationally in percentage of households with Internet access.⁶ The racial makeup of the state's population also differs significantly from that of the United States as a whole. Compared to the national average, Alabama has more than twice the proportion of African Americans (26% vs. 12.3% U.S.) and a much lower proportion of Hispanic persons (1.7% vs. 12.5% U.S.)⁷ (table 1).

An estimated 769,880 persons in Alabama, or 17.3 % of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). Alabama ranks 14th nationally in the proportion of older persons (ages 60+) residing in the state.⁸ Similar to the state's population as a whole and compared with the national average, Alabama has more than twice the proportion of African Americans ages 60+ (18.7% vs. 8.4% U.S.) and a somewhat lower proportion of Hispanic older persons (0.6% vs. 5.4% U.S.).⁹

Alabama ranks 26th nationally in the proportion of its population ages 85 and older. In 2000, 67,301 persons, or 1.5% of Alabama's population, were ages 85+.¹⁰

An estimated 423,143 family caregivers reside in Alabama. These family caregivers provide about 393 million hours of caregiving per year at an estimated value of \$3.2 billion in 1997.¹¹

Alabama has one of the lowest tax burdens of any state in the nation, reflecting the state's conservative fiscal policies.¹² Key informants noted that Alabama's health and social programs are relatively limited—historically and currently—because of the state's antitax sentiments.

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

	Alabama	United States
Total Population Characteristics		
Total Pop. ^b	4,447,100	281,421,906
% African American ^c	26.0%	12.3%
% Hispanic ^d	1.7%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	769,880	45,797,200
% 60+ ^f	17.3%	16.3%
National ranking 60+ ^g	14	NA
Pop. 65+ ^h	579,798	34,991,753
% 65+ ⁱ	13.0%	12.4%
National ranking 65+ ^j	21	NA
Pop. 85+ ^k	67,301	4,239,587
% 85+ ^l	1.5%	1.5%
National ranking 85+ ^m	26	NA
% increase 1990–2000 60+ pop. ⁿ	9.5%	9.4%
% White (60+) ^o	79.6%	82.4%
% African American (60+)	18.7%	8.4%
% Hispanic (60+)	0.6%	5.4%
% Asian (60+)	0.3%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.2%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	423,143	25,798,370
Caregiving hours (millions) (1997)	393.9	24,013.1
Value of caregiving (millions) (1997)	\$3,221.8	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$23,471	\$29,676
% of pop. below poverty (1997) ^r	16.2%	13.3%
Internet		
% of households w/Internet access (2001) ^s	35.5%	41.5%
Nat'l ranking of households w/Internet access	43	NA

a Unless otherwise noted, all data are from 2000.

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

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States.*
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States.*
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-Alabama.
- 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 younger adults with physical disabilities are administered largely through two state agencies: the Department of Senior Services and the Department of Public Health. The programs administered by these state agencies generally rely on federal funds with minimal state match; state-only-funded programs are extremely limited. Respondents pointed out that programs are designed primarily to meet basic federal requirements and to maximize federal funds while minimizing state spending.

The Alabama Department of Senior Services (ADSS) is a freestanding department that serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP. The governor appoints the executive director, who has cabinet-level status. Under contract with the Alabama Medicaid Agency, ADSS administers half of the Aged/Disabled Medicaid waiver (with the Department of Health Services) and also administers a federal Alzheimer's disease demonstration grant for dementia caregivers.

The infrastructure of Alabama's aging network is a statewide system of 13 Area Agencies on Aging (AAAs), ranging from one to 10 counties in each area. The ADSS utilizes the AAAs to provide case management under its portion of the Medicaid waiver; direct services are not provided. The majority of organizations designated as AAAs in the state are "umbrella" agencies. Typically, quasi-governmental agencies are formed by multijurisdictional agreements (e.g., regional planning commissions) for mutual planning purposes.

Alabama's Aged/Disabled Medicaid waiver was originally approved in 1981. Three agencies are involved. The Alabama Medicaid Agency¹³ is responsible for oversight as the "single state agency" for Medicaid. That agency contracts with both the ADSS and the Department of Public Health to administer the program and to deliver services to about 5,800 beneficiaries in the state (7,000 total slots).^a

The Alabama Department of Public Health (ADPH) is a freestanding department of the state government whose mission is to protect the public's health through disease prevention and the provision of public health services. The director of the department, the state health officer, is appointed by the governor and has cabinet-level status. Under contract with the Alabama Medicaid Agency, ADPH administers the other half of the Aged/Disabled Medicaid waiver (with the ADSS) under the Bureau of Home and Community Services, Division of Community Services. Unlike the ADSS, the ADPH is both an administrator and a provider of services (through the county health departments) under the Aged/Disabled Medicaid waiver.

In October 2001, the Centers for Medicare and Medicaid Services (CMS) awarded the Alabama Medicaid Agency, Long Term Care Division a Real Choice Systems Change grant. Three state agencies are involved: the Medicaid Agency (as the lead agency) and the Departments of Senior Services and of Mental Health and Mental Retardation. State officials noted that the intent of the three-year grant is to develop a home and community-based system for the elderly and for younger persons with disabilities, primarily in response to the *Olmstead* decision. Respondents noted that family caregivers are not a current focus of the grant.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

All case study respondents noted that Alabama does not have a comprehensive long-term care system, although efforts are being made to expand home and community-based care. Alabama's current long-term care system has limited home and community-based programs, constrained by low state revenues and a strong nursing home lobby. In recent years, however, the current governor, Donald Siegelman (D), has shown a strong interest in improving long-term care for the elderly and for persons with disabilities and has made one of his major health priorities the expansion of home and community-based care. To date, the multiyear effort to shift limited resources from institutional to home and community-based care has been focused on the care recipient, not on the family caregiver or the family unit.

Prior to the passage of the NFCSP under the Older Americans Act Amendments in 2000, caregiver support was not a policy issue or an interest of state leaders in Alabama. Respondents noted that Alabama is just beginning to recognize that family caregivers need support services and is now taking a more "family systems" approach. Virtually all respondents commented that family caregivers are a "new client population" in Alabama. One respondent commented, "The limited public dollars for

^a Another 1915 (c) waiver, approved in 1992 and administered by the Department of Rehabilitative Services, is known as the "homebound waiver" and targeted for the younger disabled with severe disabilities (e.g., multiple sclerosis, traumatic brain injury). Respite care was initially a covered service. It wasn't used because many of the younger disabled did not have family caregivers, however, so it was eliminated from the waiver and is no longer covered. A third 1915 (c) waiver serves individuals with mental retardation or developmental disabilities and is administered by the Department of Mental Health and Mental Retardation. In FY 2002, a new 1915 (c) waiver will begin for Alzheimer's disease and related dementias.

home and community-based care are focused on the care recipient, not the family caregiver.” Another observer noted that the traditional value system in the South is such that you “take care of your own for as long as possible.” These traditional values play a significant role in shaping public policy. In the rural areas especially, there are very few services; families who keep their loved ones at home must “go it alone” to provide care and receive virtually no support or assistance from the formal care system.

Two programs in Alabama specifically address the needs of persons with Alzheimer’s disease and their families. In the early 1990s, the legislature passed the Dementia Education and Training Act, thereby establishing a small state general fund program (approximately \$150,000 per year), administered by the Alabama Department of Mental Health and Mental Retardation, to provide limited education and training in the community on Alzheimer’s disease. In 2001, the ADSS received a three-year federal Alzheimer’s disease Demonstration Grant to States from the U.S. Administration on Aging (\$350,000 federal funds per year) to expand education on Alzheimer’s disease and to offer limited respite (through the AAAs) to dementia caregivers only. This federal demonstration is considered a “stand-alone” program, functioning apart from other Older Americans Act programs at the state and local levels.

Family and informal caregivers are not explicitly recognized as a central component of the current long-term care system, and the state does not yet have a system of support in place to assist family caregivers. The main publicly funded programs to address caregiver needs are the new federally funded *Alabama Cares* program administered by the ADSS (funded under the NFCSP); limited respite care through the Aged/Disabled Medicaid waiver; and the small, state-funded Alzheimer’s education program and the federal Alzheimer’s demonstration grant targeted to dementia caregivers.

Alabama Cares—the name for the NFCSP in the state—is the first program in Alabama to focus explicitly on the needs of family caregivers. Through implementation of the new federal program, the ADSS intends to build caregiver support into existing state infrastructures, primarily through the AAAs, coordination with other state departments (e.g., ADPH) and long-term care planning efforts and partnerships with existing agencies and organizations in the community.

PROGRAM BACKGROUND/DEVELOPMENT

The original impetus for Alabama’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. Prior to passage of the NFCSP, no statewide caregiver support program existed in the state. Alabama’s ADSS began planning for the establishment of the new program in March 2001.

Similar to the state’s other health and social service programs, the ADSS wanted to centralize policymaking and administrative decisions at the state level for the new caregiver support program. To promote public awareness of the statewide program and to assure statewide standards, the ADSS named the new caregiver support program *Alabama Cares: Caregiver Assistance with Resources, Education and Services*. At the time of the site-visit interviews, ADSS and the AAAs described themselves as being in the start-up of program development; the state and aging network had not yet completed a full year of implementation.

When developing *Alabama Cares*, the state looked at caregiver support programs in New Jersey, North Carolina and Wisconsin as models. The 13 AAAs held public forums and focus groups to involve caregivers in the planning process at the local level. The Alabama Department of Senior Services required the AAAs to have an approved area plan amendment before going out to bid for caregiver support services. Programs and services were phased in through the state's 13 AAAs between July 2001 and March 2002. The ADSS strongly recommended that each AAA establish the position of *Alabama Cares* coordinator for the purpose of managing caregiver support services at the local level. When the ADSS began planning for the program in the Spring of 2001, the department recognized that implementation of a successful statewide program would require a dedicated staff person to coordinate statewide efforts. The state *Alabama Cares* coordinator was hired in August 2001.

Most rewarding: Key informants noted the most rewarding aspect of the program's development has been the positive feedback from the community, from both family members and service providers. Prior to the development and implementation of *Alabama Cares*, there was no explicit caregiver support program in the state. Families have commented that the program "gives people hope." The respondents also stated that the flexibility from the Administration on Aging (AoA) has enabled Alabama to (1) develop statewide standards and (2) allow the AAAs flexibility to be creative in meeting caregiver needs.

Biggest challenge: According to the key informants of state officials and stakeholders, there were two major challenges of the program's development in the first year of program start-up. First is a lack of direct service workers to provide respite care, particularly in rural areas. The state is experiencing a growing shortage of direct care workers in long-term care settings. Many of the providers for respite care under *Alabama Cares* are also Medicaid waiver providers. Finalizing service contracts with providers so that families have a choice and range of service options at the local level has been a real challenge. Second, when the ADSS was designing the caregiver support program, it wanted to include a voucher program for respite as well as supplemental services that would be uniform across the AAAs. However, this first year the AAAs were not able to reach consensus on the amount of the voucher per family caregiver. As a result, families can receive more respite care or supplemental services in some of the state's regions than in other areas. While most of the AAAs voucher at \$500 per family client per year, some AAAs voucher at higher amounts, up to \$1,000 per family client per year.

To ensure that family caregivers are indeed part of the ongoing planning process for *Alabama Cares*, the ADSS, under contract with the University of Alabama at Birmingham, conducted a statewide long-term care survey in the summer of 2002, which included a series of questions on family and informal caregiving. Results will be used to shape the state's next four-year state plan on aging (FY 2003-06) and to provide caregiver data to state leaders involved in Alabama's long-term care planning efforts.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—*Alabama Cares* received \$1.74 million in federal funds, with \$579,000 in state match, for a total of \$2.3 million, or 4.6% of the overall ADSS budget. The majority of the federal funds were carried over to FY 2002. In FY 2002, the federal share of NFCSP funds was increased to \$1.98 million.

In FY 2001, the total cost of services under the Aged/Disabled waiver in Alabama was \$36.8 million. Of those funds, 15%, or \$5.4 million, was spent overall for respite care under the waiver. These two sources of limited funds and the federal Alzheimer's grant are essentially the only public dollars in the state to support and strengthen family caregivers of older persons.

Alabama 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. In FY 2001, Alabama received about \$115 million in tobacco settlement revenues. Of those funds, about \$37 million were transferred to the state's general fund for Medicaid. Another \$6.3 million were specifically used for the Aged/Disabled Medicaid waiver, and \$1.8 million were used for the Senior Services Trust Fund to provide home and community-based services. Respondents commented that even though a relatively small portion of the tobacco revenues are targeted to aging-related programs, this revenue source is vital for aging programs, given the lack of state-specific funds for support services.

Key informants described the current budget situation in Alabama as “very lean” and “fragile.” The downturn in the economy has not thus far impacted services to support family caregivers. The state has not experienced any problems in maintaining the required 25% state match for *Alabama Cares*.

PROGRAM ADMINISTRATION

The ADSS sees its role in the development and implementation of the state's first caregiver support program to be in the areas of oversight, policy development, technical assistance, funding, publicity and program awareness. Policy development and program administration are centralized at the state level and moving toward a single point of entry at the AAAs. The ADSS emphasizes the development of statewide policies and standards to ensure a consistent approach to caregiver support with flexibility to meet the needs of family caregivers at the local level. The ADSS develops policies for the program with input from the AAAs.

The ADSS has focused resources on publicizing *Alabama Cares* by developing a statewide brochure, posters and a website. The posters have been placed in all of the 350+ senior centers in the state. To get a consistent message out to the public about the new program, the ADSS has developed a logo for *Alabama Cares* to promote an “identity” for the new program. The state *Alabama Cares* coordinator is a strong advocate for family caregivers and frequently speaks throughout the state to increase awareness of caregiver needs and the new Alabama support program.

State Medicaid officials did not identify a role for their agency with regard to caregiver support services in Alabama. Case study respondents frequently noted that the concept of “family caregiver support” was new to the state, even though respite care has long been covered under the Aged/Disabled Medicaid waiver.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for *Alabama Cares* is consistent with federal requirements under the Older Americans Act; the program is for family or informal caregivers of any age who provide care to persons 60 years or older, as well as caregivers ages 60 and over who care for children ages 18 or younger.^b 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 have cognitive impairment. A uniform, statewide sliding fee scale is used for services such as respite care. Cost-sharing is based on the care recipient's income, rather than on the caregiver's household income. Most family caregivers served to date have been low income (below the poverty line) or low to moderate income, ADSS staff noted. The family caregiver is considered the client in the program.

Client assessment standards are uniform across the state. The ADSS in partnership with the AAAs adapted the existing client assessment tool to include a caregiver component; thus the assessment focuses on both the care recipient and the family caregiver. There are about 10 questions for the family caregiver, representing a required minimum data set. Some AAAs have added additional assessment items to their tools. As part of the assessment process, informal care is considered on a case-by-case basis in the authorization of paid services for the care recipient. The assessment with the care recipient and the family caregiver is generally conducted in person, usually in the home. Follow-up with a family client is required at least two times per year.

Eligibility for the Aged/Disabled Medicaid waiver program is consistent with federal requirements; it includes recipients of Supplemental Security Income (SSI) or State Supplementation who meet the medical criteria for Medicaid nursing home level of care. Respondents noted that the care recipient is the identified client in the program. One observer from ADPH believed that both the care recipient and the family caregiver should be considered the "client" in the waiver program, because respite care is a covered service in Alabama.

A standard application is required for all Medicaid services, including waiver services in Alabama. This is considered the assessment, and client eligibility is reassessed annually. Consistent with Medicaid policy in general, respondents noted that the extent of informal care (i.e., whether or not the care recipient has a family caregiver) is considered in the authorization of paid services for the care recipient. Respondents acknowledged that although the state *should* assess the family caregiver's needs and ability to provide care, it currently does not; only the care recipient is assessed.

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

SERVICES

Rather than focus on one specific service category, the state required that each of the AAAs make available all NFCSP core services to family caregivers in order to develop a multifaceted system of caregiver support. Following the standard assessment, the intent is to give caregivers the following menu of services to choose from to help meet their needs:

- ◇ Information
- ◇ Assistance
- ◇ Individual counseling, support groups and training
- ◇ Respite care (voucher program)
- ◇ Supplemental services (voucher program)

At the time of the site visit (March 2002), about 450 family caregivers had received services through *Alabama Cares*.

Alabama's AAAs typically are not direct service providers, but provide largely information and assistance, assessment and case management. AAAs are permitted to be direct service providers but first must request a waiver from the state. Some AAAs have requested and received waivers to provide counseling to caregivers in-house.

All 13 AAAs subcontract with local providers for respite care through a voucher program, including in-home, adult day services (where they exist), overnight in a facility and weekend respite options. Respondents noted that the cost per hour for a respite provider in Alabama is typically between \$10.00 and \$14.50 per hour. The family caregiver gets the voucher and a list of service providers for respite and supplemental services (e.g., home modifications). The family client is responsible for selecting a provider and arranging services. In Alabama, about 70 to 80% of the AAAs' NFCSP allocation is for respite assistance. Because of the newness of the program, including the concept of "respite care" and "getting a break," the state *Alabama Cares* coordinator has encouraged the AAAs to focus attention on education and training, particularly in the start-up year of the statewide program. Education is needed to inform family caregivers about the benefits of respite care for themselves as well as for the care recipient.

Given the limited funding overall, there is a cap on the amount of respite and supplemental services per family caregiver. The cap varies from one AAA to another, typically at \$500 per year, resulting in a limited respite benefit. State officials noted that a few AAAs are vouchering for respite at up to \$1,000 per year. According to key informants, the respite component, however limited in funding, is filling an important service gap by providing at least minimal respite assistance—as a preventive service—to family caregivers who are not eligible for respite under the Medicaid waiver because their loved one is not severely functionally impaired.

Under the Aged/Disabled Medicaid waiver, respite services are the only service type specifically provided for family caregivers, up to 720 hours per year. Covered respite services include both skilled and unskilled in-home respite assistance and adult day health services. Waiting lists exist for all Medicaid waiver services, not just for respite care. Respondents expressed hope that the new *Alabama Cares* program will offer respite assistance to family caregivers who don't qualify for waiver services so that they can get some relief: to those in the low-middle income group who care for loved ones not severely functionally disabled. The Medicaid waiver officials identified the need to provide education and skills training for caregivers. This is currently not covered under their waiver, but respondents pointed out that many families lack the necessary skills to provide care at home.

Major services needed by caregivers: At the ADSS, supplemental services were identified as the major service category needed by family caregivers. Supplemental services are allowable under the federal NFCSP on a limited basis to complement care provided by caregivers. (No more than 20% of the federal funding should be used in this service category.) Examples of supplemental services provided in Alabama include chore services (e.g., putting running water in a caregiver's home that doesn't have the necessary equipment), wheelchair ramps, emergency response systems and barber services in the home. State officials at the ADSS also identified major service needs as education and training about caregiver issues in general as well as respite care. Several waiver key informants pointed to the need for better resource coordination to guide families through the service delivery system. Stakeholders noted respite care as the major service needed by family caregivers, followed by supplemental services (e.g., consumable supplies, home modifications).

Table 2. Family Caregiver Support Services in Alabama

Program	<i>Alabama Cares</i>	Aged/Disabled Medicaid Waiver
State Administrative Responsibility	Alabama Department of Senior Services	Alabama Medicaid Agency contracts with Alabama Department of Senior Services (ADSS) and Department of Public Health (ADPH)
Local Service Delivery	AAAs ^a —information, assistance, assessment & case management ^b (AAAs are not direct service providers but contract for respite care & supplemental services)	AAAs—case management only (under contract with ADSS) County Public Health Departments—case management and service provision (under contract with ADPH)
Funding Source	Older Americans Act, Title III-E	Medicaid 1915(c) waiver
Expenditures FY 2001	\$1.74 million ^c (for all caregiver support services)	\$5.4 million (for respite care only)
Client Population	Family & informal caregiver	Care recipient
Eligibility Criteria		
Age	60+ care recipient Family caregivers of any age	18+ care recipient
Income	None	SSI or State Supplementation
Functional Ability	For respite and supplemental services—at least 2 ADLs or cognitive impairment for care recipient	Nursing home level of care
Uniform, Statewide Caregiver Assessment	Yes	No
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite care
Respite Cap	Varies by AAA from \$500 to \$1,000/year \$500/year average	720 hours/year
Consumer Direction	Not formally. Some elements of consumer direction are offered. Family caregivers can choose own provider from voucher list of home care agencies and can set number of hours of help they need. They can also purchase goods & services (e.g., consumable supplies, home repairs) under the supplemental services category.	No
Family Caregivers Paid as Respite Providers	No	No

a AAAs = Area Agencies on Aging.

b Some Alabama AAAs have received a waiver to provide caregiver counseling in-house.

c Federal funds only; the majority of federal funds were carried over to FY 2002.

CONSUMER DIRECTION

Neither *Alabama Cares* nor the Aged/Disabled waiver offers a formal consumer-directed option, and neither program permits payment to family caregivers to provide respite care. Respondents commented that there is the perception in the state that quality control and fiscal accountability could be lost if consumer direction were allowed. The ADSS observers commented that the respite and supplemental services voucher system of *Alabama Cares* makes some elements of consumer direction available. Family caregivers can choose their own provider from the list of voucher home care agencies, for example, and can set the number of hours of help they need. Allowable benefits under the supplemental services voucher include goods and services—whatever the caregiver needs to keep a loved one at home.

The Medicaid officials pointed out that Alabama would soon be permitted to offer consumer direction to younger persons with disabilities only under their homebound waiver.

QUALITY ASSURANCE AND EVALUATION

The state has developed a uniform client enrollment and tracking procedure for family caregivers served in *Alabama Cares*. All AAAs are required to use the standard assessment form for the caregiver (known as the Client Enrollment Form), which includes basic demographic data on the family caregiver (e.g., relationship to care recipient, age, gender, race), an assessment of informal supports and constraints on the caregiver (e.g., employed, lacks knowledge/skills), a stress vulnerability survey and a nutritional risk survey. The information is then transferred to the state's information management system. Caregiver data collection is in a manual format. The state is in the process of automating the entire data collection system for a coordinated, centralized statewide client tracking system.

Alabama is collecting data on caregiver outcomes through its uniform assessment process, particularly the stress vulnerability survey. This 21-item measure was developed by Lyle Miller and Alma Dell Smith, psychologists at Boston University Medical Center, and adapted for use by ADSS and Alabama's AAAs.

Given the early stage of development of *Alabama Cares*, the state has made strong progress in setting and refining program standards, developing a uniform yet flexible approach to service delivery and structuring quality assurance activities to ensure that services provide value to family caregivers. The state, in partnership with the AAAs, has developed regional program standards and minimal indicators for a number of functions, including client file maintenance, coordinator training, media activities, outreach, partnership development and targeting for underserved populations. In this way, the state ensures a consistent, uniform approach to serving family caregivers. Exhibit A highlights examples of program standards and minimum indicators to track performance.

Under the Aged/Disabled Medicaid waiver, respondents noted that no information is currently collected on family caregivers. In general, this is because the "client" of the program is viewed as solely the care recipient.

Exhibit A. *Alabama Cares* Selected Regional Program Standards: Targeting Underserved

<i>Definition of Targeting Underserved:</i> Specifically directing information and/or programs to the socially and/or economically underserved through various outreach methods.	
Standard	Minimum Indicator
1. Each Coordinator will strive to develop and/or use culturally sensitive material for ethnic caregivers.	1. Coordinators should research ethnicities and their respective feelings towards the receipt of outside assistance as well as the traditional role of the family in caregiving.
2. Each Coordinator will strive to alleviate the reservations held by various groups about enlisting the assistance of social service agencies.	2. Coordinators should develop a trusting relationship and credible reputation with community leaders in order to be more effective and accepted in the community.
3. Each Coordinator will strive to hold meetings, trainings, etc., in locations that are easily accessible and comforting to the family caregiver.	3. Coordinators should hold meetings in the “comfort zones” in the underserved community, so as to foster greater participation of, and connectivity with, family clients.

Source: Alabama Department of Senior Services, Regional Program Standards, October 2001.

SYSTEMS DEVELOPMENT

Alabama Cares has been well received in its first year of start-up by both family caregivers and service providers in the community, according to the key informants. It has been important to provide centralized policy development, program standards and administrative oversight while at the same time encouraging flexibility in service delivery at the local level to meet family needs.

Key informants from the Medicaid waiver program hope that the new federal dollars for family caregiver support under *Alabama Cares* will assist family members who “fall between the cracks”—those who are ineligible for Medicaid services but who have few resources to purchase services on their own.

At the time of the site visit, the state had not yet completed the first year of program implementation. The state, in partnership with the AAAs, will continue to refine the process and procedures and to focus on increasing the visibility of family caregivers in Alabama.

In the emerging system of support, caregiver services are coordinated at the local level by the 13 AAAs. At the state level, services are coordinated at ADSS, primarily through the state *Alabama Cares* coordinator, who interacts frequently with coordinators at the AAA level. Respondents during the Medicaid interview noted that caregiver support services are not yet coordinated at the state level, however.

Alabama does not have a body whose mission is to coordinate family caregiver support services across state departments. The development of a long-term care system is just beginning to take hold in the state, and the ADSS is interested in including family caregivers in policy discussions in the future. All respondents stated that a goal of the new *Alabama Cares* program is to integrate the caregiver support program into Alabama’s emerging long-term care system rather than to develop a stand-alone program.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In January 2000, the governor appointed a long-term care task force to advise his administration on how to improve long-term care services for older persons and to promote home and community-based care. Key informants noted that family caregiving issues have not been an issue of debate.

Alabama received a grant from the Center for Health Care Strategies to develop a comprehensive plan in response to the *Olmstead* decision. Officials from the long-term care division of the Alabama Medicaid Agency are spearheading this effort. ADSS officials expressed some frustration that the state has not involved family caregivers of the elderly in the planning process. *Alabama Cares* was a brand-new program when *Olmstead* planning began, and with minimal funding and limited staff, efforts were directed to “getting the caregiver support program off the ground,” rather than to developing policy in long-term care. Although the primary focus of the governor’s task force has been to seek ways to expand home and community-based services for older people and for younger persons with disabilities, family caregiver issues have yet to be addressed in the state plan.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high, medium, low) is placed on caregiver support?” Key informants interviewed felt that, overall, Alabama tended to place “low” to “low-medium” priority on caregiver support services. One state official did not offer an opinion. State officials and stakeholders did not differ in their responses.

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

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

1. The general support afforded to family caregivers—just knowing the program exists is a “life line” to families
2. The new focus on caregiver assessment—to better understand the needs of individual caregivers and the impact of caregiving on their quality of life
3. Respite care—to give families a break, particularly for family caregivers not eligible for respite under the Medicaid waiver

The following challenges were reported:

- ✧ Lack of trained direct care providers
- ✧ Need to get the aging network and those who work with the elderly to broaden their focus to address the needs of family caregivers, not just the needs of the older person, as client
- ✧ Limited funding to meet the needs of individual caregivers (Older Americans Act and Medicaid)
- ✧ Lack of skills training for caregivers (Medicaid)

Major lesson learned: Alabama's respondents expressed a belief that "the need is great and resources are few" in their state. In the first year of start-up of *Alabama Cares*, several respondents commented that some families who need help the most are reluctant to use services. Family caregivers need to be educated about service options and how they can be of help to both the caregiver and the care recipient.

Other case study respondents from the Aged/Disabled Medicaid waiver program pointed to the need for more flexibility by the federal government (i.e., CMS) and the state in allowing more consumer direction, including paying families to provide care. To address this and other issues, the state plans to review its entire Medicaid program over the next few years. One observer commented, "Medicaid rules are not flexible. Now, Alabama consumers are on the Internet and they know that other states are more flexible than we are. We must allow more flexibility to meet family needs."

Opportunity for expanding caregiver support: All Alabama respondents were pessimistic about new initiatives or state expansion of state-funded programs to support and strengthen family caregivers over the next three to five years. Alabama has historically not provided health and human services programs beyond minimum federal requirements or established programs with state revenues. Nevertheless, over the past few years, the budget for the state's ADSS has grown from \$30 million to \$50 million, and the key informants—both state officials and stakeholders—want to keep the momentum for growth and to focus on caregiver issues.

Recommendations for other states: Key informants offered several recommendations based on their experience to date:

- ✧ Don't reinvent the wheel.
- ✧ Involve all stakeholders in planning and program implementation.
- ✧ Pursue partnerships and collaborate.
- ✧ Be flexible and don't overregulate.
- ✧ Recognize that caregiver needs and situations vary (e.g., rural vs. urban, ethnic differences, income level).
- ✧ Be optimistic.

NOTES

- 1 MapStats-Alabama, *www.fedstats.gov* (June 2002).
- 2 Alabama Department of Senior Services, *State Plan on Aging: 1999-2002*.
- 3 Ibid.
- 4 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/newsrel/spi0401.htm* (2001).
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- 6 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.
- 7 Ibid.
- 8 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group*, *www.aoa.gov/aoalstats/2000pop/percentxstate.html* (April 1, 2000).
- 9 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Percent of Persons 60+ by Race and Hispanic Origin-by State-2000*, *www.aoa.gov/aoalstats/2000pop/percent60plusrace-ho.html*.
- 10 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Profile of General Demographic Characteristics for the United States*, *www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html* (2000).
- 11 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).
- 12 B.A. Ormond and A. Wigton, *Recent Changes in Health Policy for Low-Income People in Alabama*.(Washington, D.C.: The Urban Institute, 2002).
- 13 The Alabama Medicaid Agency, the state's "single state agency" for Medicaid, directly administers the nonwaiver home and community-based Medicaid program.