Family Caregiver Support:

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

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IOWA

Overview

Iowa is a midwestern state with a relatively homogenous, rural population. The state ranks fourth in the country in the proportion of residents ages 60 and older, and second in the proportion of persons ages 85 and older. Iowa's current long-term care system provides a mix of institutional and home and community-based care services, with a decentralized approach to best meet local needs. State-only–funded programs for the elderly and for persons with disabilities are comparatively limited, which may have been influenced by a strong nursing home lobby. In the last few years, however, there has been a greater focus on developing a range of programs and services to offer consumer choice, partly because of an attempt to reduce nursing home costs and unused nursing home beds.

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 Iowa's state budget. The state's developing caregiver support services are characterized by:

- Utilization of the Iowa Association of Area Agencies on Aging as the coordinating body for statewide policymaking and administration
- Flexibility to meet the individual needs of family caregivers at the local level
- Consumer choice

Iowa respondents noted that the major service needs of family caregivers are (1) respite care, (2) assistance navigating the system and (3) help with physical needs, such as transportation.

Introduction

Iowa represents a state that is now explicitly providing caregiver support as a result of the passage of the NFCSP. The project team conducted a site visit between May 6 and 7, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Iowa Department of Elder Affairs
- *Iowa Family Caregiver* (NFCSP funded)

Iowa Department of Human Services
- Aged/Disabled Medicaid waivers
- Real Choice Systems Change grant

Stakeholders interviewed were from:

- Iowa Association of Area Agencies on Aging
- Alzheimer's Association

Two programs are featured:

1. *Iowa Family Caregiver*
2. Aged Medicaid waiver

Background

Iowa is a midwestern state that ranks 30th in the nation in population density, with 2.9 million people residing in 99 counties.[1] The state has substantial rural populations, with relatively little racial and ethnic diversity. In 2000, personal income per capita was $26,723, compared to the national average of $29,676.[2] About 10% of Iowa's population live below the federal poverty level (vs. 13.3% U.S.).[3] Iowa ranks 33rd nationally in percentage of households with Internet access.[4] The racial makeup of the state's population differs significantly from that of the United States as a whole. Compared to the national average, Iowa has a significantly smaller proportion of African Americans (2.1% vs. 12.3% U.S.) and a much lower proportion of Hispanic persons (2.8% vs. 12.5% U.S.)[5] (table 1).

An estimated 554,573 persons in Iowa, or 19% of the state's population, were 60 or older in 2000 (vs. 16.3% U.S.). Iowa ranks fourth nationally in the number of persons ages 60+ residing in the state.[6] Similar to the state's population as a whole, and compared to the national average, Iowa has a significantly smaller percentage of African Americans ages 60+ (0.9% vs. 8.4% U.S.) and of Hispanic older persons (0.6% vs. 5.4% U.S.).[7]

Iowa ranks second in the country in the proportion of its population ages 85 and older. In 2000, 65,118 persons, or 2.2% of Iowa's population, were ages 85+.[8]

An estimated 277,860 family caregivers reside in Iowa. These family caregivers provide about 258 million hours of caregiving per year at an estimated value in 1997 of $2.1 billion.[9]

Although Iowa has many facility-based long-term care options, a major effort has been made in recent years to convert nursing homes to assisted living and adult day health facilities. Like many states, Iowa experienced substantial growth in its tax base and state revenue in the 1990s. As a result of this growth, starting in 1995, the state legislature enacted substantial tax cuts, to the tune of approximately $500 million annually.[10]

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

	Iowa	United States
Total Population Characteristics		
Total Pop.[b]	2,926,324	281,421,906
% African American[c]	2.1%	12.3%
% Hispanic [d]	2.8%	12.5%
Older Population Characteristics		
Pop. 60+[e]	554,573	45,797,200
% 60+[f]	19.0%	16.3%
National ranking 60+ [g]	4	NA
Pop. 65+[h]	436,213	34,991,753
% 65+[i]	14.9%	12.4%
National ranking 65+ [j]	4	NA
Pop. 85+[k]	65,118	4,239,587
% 85+[l]	2.2%	1.5%
National ranking 85+[m]	2	NA
% increase 1990–2000 60+ pop.[n]	0.2%	9.4%
% White (60+)[o]	97.7%	82.4%
% African American (60+)	0.9%	8.4%
% Hispanic (60+)	0.6%	5.4%
% Asian (60+)	0.4%	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)	277,860	25,798,370
Caregiving hours (millions) (1997)	258.6	24,013.1
Value of caregiving (millions) (1997)	$2,115.6	$196,426.7
Economic Characteristics		
Per capita income [q]	$26,723	$29,676
% of pop. below poverty (1997)[r]	9.9%	13.3%
Internet		
% of households w/Internet access (2001)[s]	39.0%	41.5%
Nat'l ranking of households w/Internet access	33	NA

a Unless otherwise noted, all data are from 2000.
b MapStats-Iowa, *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 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/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-Iowa.
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 Iowa Department of Elder Affairs (IDEA) and the Department of Human Services (DHS). In recent years, Iowa has sought to expand resources for home and community-based services as its aging population has grown. One key informant pointed out that the current emphasis in Iowa is on maximizing federal funds while minimizing state spending.

Iowa's long-term care system is characterized by shared responsibility for care between state and county governments. Many of Iowa's 475 nursing homes are county-run. Home and community-based services are delivered by the state's private provider network, which provide the majority of services in Iowa's communities.[11] Area Agencies on Aging (AAAs), on the other hand, carry out assessments and care management.

The IDEA 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.

The infrastructure of Iowa's aging network is a statewide system of 13 nonprofit AAAs that provide services to areas ranging from three to 10 counties. Home and community-based services to the older population are coordinated at the local level through the AAAs and a well-developed care management system. Each of Iowa's counties has a care management team facilitated by the AAA. Public health nurses from county health departments generally determine functional eligibility for programs, while DHS staff determine financial eligibility. The rest of the care management team, who

meet on a regular basis, consist of volunteers from the faith communities, private providers (e.g., hospitals, nursing facilities, adult day care) and other representatives as needed (e.g., police, attorneys). Older persons as well as the family caregiver are always invited to the team meeting. Most of the AAAs contract out for services rather than provide support services directly. The Iowa Association of AAAs (I4A) is relatively active, with several paid staff members.

DHS is Iowa's "single state agency" for Medicaid. DHS administers Iowa's Aged Medicaid waiver, which was originally approved in 1989.[a] When it was first approved, the state legislature mandated that four state departments (Elder Affairs, Public Health, Human Services and Inspections and Appeals) come together to develop a long-term care unit. The intent was for the body to coordinate administration and oversee planning of services to older adults.[12]

The DHS has administrative responsibility for the waiver. Currently, the IDEA's only role with regard to the waiver is to provide case management through a contract with the DHS. In turn, the IDEA subcontracts with the AAAs to provide case management to waiver participants. The Aged Medicaid waiver serves about 4,300 participants.[b]

Overview of State System of Caregiver Support

Iowa has the fourth-highest proportion of persons ages 60 and older in the nation. Although the NFCSP represents the first explicit effort to support family caregivers in Iowa, state leaders have been encouraged because of the sizable aging population to focus efforts on the development of home and community-based alternatives, including some support for family caregivers through respite care. One respondent indicated that helping older persons maintain their independence is the top priority in Iowa, followed by helping the family caregiver.

Iowa's efforts include establishment of the Senior Living Trust Fund in 1999 by the Iowa legislature. The trust was specifically developed with state general funds to expand home and community-based service options by making available some of the state's 8,000 unused nursing home beds to provide space for adult day health, respite care and assisted living care.[13] The trust was part of a larger legislative effort enacted, known as the Comprehensive Senior Living Program. The goal of the legislation was to create a comprehensive, long-term care system focusing on consumer direction, balance in offering institutional and home and community-based services and support of the quality of life of older Iowans.[14] Both the legislative and executive branches appear to support this initiative; however, $20 million was transferred in FY 2002 from the trust to pay for other state services.[15] At the time of the site visit, the IDEA had administered $4.1 million of the trust to provide local services through the state's AAAs.

a In Iowa, the Aged Medicaid waiver is referred to as the Elderly Waiver.

b The Department of Human Services has six Medicaid home and community-based service waivers. They include the Ill and Handicapped waiver, serving those from birth to age 65; the Aged Medicaid waiver, serving those ages 65+; the Brain Injury waiver; the Mental Retardation waiver; an AIDS/HIV waiver; and a Physical Disability waiver, serving individuals ages 18 to 64.

Iowa state officials have also tried to shift some focus from institutional care to noninstitutional care by focusing policy attention on developing affordable assisted living and developing adult day health oversight. Since 1988, Iowa has committed state funds to support Alzheimer's Association chapters throughout the state. However, due to state budget shortfalls, state funds for Alzheimer's services were discontinued in FY 2002. In addition to putting state funds toward Alzheimer's Association chapters, the state has been awarded a federal Alzheimer's Disease Demonstration Grant to States, which has been funded since FY 2001. Iowa has also established the Case Management Program for the Frail Elderly, funded through a mix of state general funds and federal funds through the Aged Medicaid waiver.

Iowa Family Caregiver—the name for the NFCSP in the state—is the first program in Iowa to focus explicitly on the needs of family caregivers. The IDEA, through implementation of the new federal program, intends to build caregiver support into existing state infrastructures, primarily through Iowa's AAAs.

Recently, Iowa was also awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The DHS Division of Mental Health/Development Disabilities has primary responsibility for the grant. Goals of the grant are to move the disability services system away from the traditional medical model toward a model driven by consumer choice, with home and community-based options, and to design an individualized, consumer-centered process to assess individual preferences and needs. Respondents noted that family caregivers of the elderly are not viewed as a priority target group under this grant.

The DHS has implemented several programs that expand focus on home and community-based services. The first is of the consumer-directed attendant care (CDAC) program, implemented through a change to Iowa's Medicaid state plan. CDAC allows a family caregiver to be a paid provider under all of Iowa's Medicaid waivers. DHS also administers a family support subsidy (the In-Home Health Care program) and a rent subsidy program. Both of the subsidies could help ease some of the financial burden associated with caring for a chronically ill family member; the In-Home Health Care program also provides respite services and care management.

When asked if family and informal caregivers were recognized as a central component of a comprehensive long-term care system, case study key informants varied in their opinions. One respondent observed that help from family, friends and neighbors was taken for granted and that the state of Iowa recognizes that it would "be in dire shape without family caregivers."

Program Background/Development

The original impetus for Iowa's family caregiver support program was the passage of the Older Americans Act Amendments of 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. When the IDEA began its planning process for the new program, it brought the AAAs together to look at various options to develop a coordinated system of caregiver support in the state. One stakeholder pointed out that the planning sessions have focused on a coordinated information and referral system.

The Iowa Association of AAAs (I4A) developed the name *Iowa Family Caregiver,* which appears on Iowa's NFCSP website as well as on its publicity materials, in order to promote a consistent, statewide identity for the program.

Most rewarding: State officials of the IDEA noted the most rewarding aspect of *Iowa Family Caregiver* has been "to allow us to focus on the family caregiver. We have always helped caregivers but not explicitly." Medicaid officials indicated that the most rewarding aspect of the Aged Medicaid waiver was the ability through it to allow older persons to remain at home and in their communities, which allows consumers more control over their lives. Medicaid officials did not comment on the impact of Medicaid waiver services on family caregivers.

Biggest challenge: According to key informants, designing a public awareness campaign to effectively reach families when they most need it has been a challenge. Respondents expanded on this idea by indicating that family members are challenged to identify themselves as family caregivers, and professionals are challenged to provide services when the caregiver needs it. The administration of multiple funding streams was also identified as a challenge.

Funding

In FY 2001—the first year of federal funding under the NFCSP—*Iowa Family Caregiver* received $1.4 million in federal funds. In FY 2002, the federal share of NFCSP funds was increased, with Iowa's allocation increasing to $1.8 million, or about 6% of IDEA's total budget.

In contrast, in FY 2001, total expenditures under the state's Aged Medicaid waiver were $12.6 million, or about 3% of the total DHS Medicaid budget. Key informants were unable to identify the proportion of the Aged Medicaid waiver spent on respite care.

Iowa received nearly $56 million in tobacco settlement funds during FY 2000 and about $60 million in FY 2001. Iowa plans to use significant funds from the tobacco settlement toward home and community-based services. The Iowa legislature established a health care endowment, which will receive tobacco settlement funds as well as general revenue, earmarking funds for capital improvement projects and health care services.[16] In addition to this, the FY 2003 proposed budget includes several allocations for tobacco funds, including $313,565 for the state match for the Aged Medicaid waiver and $1.1 million for an expansion of respite care services. State officials also indicated that tobacco funds have been used in part of the state efforts to transition nursing homes and assisted living facilities to use for facility-based respite, under the state's Senior Living Trust.

When asked to describe the current budget situation in their state, Iowa key informants indicated that they were suffering, like all other states. The IDEA has been able to use funds from the Senior Living Trust and NFCSP dollars to compensate for some budget cuts. The IDEA has reduced some case management and direct service funding going to the AAAs. One stakeholder pointed out that home and community-based services had gotten new funding, even though the state budget was not in good shape.

Officials from the DHS indicated that the state was "in crisis," and said that they were "scrambling to keep what we have." The department has had to lay off some staff and cut services.

According to the National Conference of State Legislatures, Iowa's Medicaid program is facing $18.6 million in service cuts necessitated by a 4.3% across-the-board cut.[17] In February 2002, the Iowa legislature mandated an additional 3% across-the-board cut.

Program Administration

Iowa's AAAs play a predominant role in administering programs that serve older persons, specifically with regard to implementation of the NFCSP. As one key informant noted, "Iowa has a local system of care, not a state system." The IDEA serves as a pass-through for all Older Americans Act funds, including the NFCSP, with the I4A serving as primary coordinator of the program.

Several key informants commented that Iowa's aging services have historically been administered through shared responsibility between the IDEA and the state's AAAs. Policymaking and administrative decisions are centralized through I4A, rather than through IDEA. *Iowa Family Caregiver* is administered by a caregiver coordinator, who previously served (for 12 years) as executive director of the IDEA. The coordinator began in March 2001.

The IDEA sees its role in the development and implementation of the state's first caregiver support program as one of oversight. State officials at the IDEA said that they also seek other sources of funding and are now looking at the administration of similar programs in other states. One stakeholder commented that the IDEA should have an increasing role in monitoring the caregiver support program and examine outcomes. Although the IDEA and I4A work collaboratively to administer the caregiver program, the I4A handles the majority of program administration issues while keeping IDEA informed of programmatic issues. I4A's board of directors must approve changes in *Iowa Family Caregiver* policies and services. IDEA staff overseeing the *Iowa Family Caregiver* program at the state level devote 10% of their time to this program.

I4A has focused on developing a statewide approach, encouraging AAAs to develop support services that best meet local consumer need. Referring to the developing caregiver support program, one respondent indicated that one of the keys to a successful program is to "under-promise and over-deliver."

Each AAA in Iowa has hired a caregiver specialist to assist consumers with *Iowa Family Caregiver* services. Further, each AAA pools some funding for development of a joint website, resource development, a toll-free number for a single point of entry and development of a marketing/publicity and education plan, all part of an effort toward a consistent, statewide approach. In 2001, each AAA committed 20% of its funds to I4A for this effort. For 2002, each contributes 15%. Two of the 13 AAAs opted out of the pooled funding approach but do contribute funds for website development and other services.

State Medicaid officials identified their role as funder of the Aged Medicaid waiver, policy developer, overseer and, in contract with agencies, provider of training. State officials characterized their relationship with program managers at the local level as a "cooperative effort." In developing policies for caregiver support services, respondents indicated that they constantly refine rules and regulations to meet the needs of consumers and their families, with a focus on developing consensus among interested parties. Their intent is to achieve uniformity among all of Iowa's Medicaid waivers, while retaining flexibility to meet individual needs at the local level. Medicaid officials put forward the

example of changing the respite rules in all of their Medicaid waivers, which, after two years to complete, resulted in families being paid and in more flexible reimbursement rules.

Program Eligibility/Assessment Process

Iowa Family Caregiver: Eligibility is consistent with federal requirements under the Older Americans Act. Family or informal caregivers of any age who provide care to persons 60 years and older are eligible, as are caregivers ages 60 and older who care for children ages 18 or younger.[c] 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). There are no income eligibility requirements.

Iowa's case management is an integral part of all of its programs serving older persons, including *Iowa Family Caregiver*. One respondent indicated that it was, "almost impossible for us to talk about the NFCSP without talking about case management." With regard to the case management program, the assessment process is uniform across the state and contains a brief, standard caregiver assessment, approximately six questions long, including basic demographic information, the ability of the caregiver to provide care and some indication of stress level. Now that the NFCSP has been implemented, responses to the caregiver questions trigger a referral for the family caregiver from the older person's case manager to a caregiver specialist at the AAA. Within *Iowa Family Caregiver* specifically, however, there are not uniform assessment standards. Although the AAAs operate both the case management program and *Iowa Family Caregiver,* key informants noted that there is no uniform intake or assessment specifically under the program. In fact, not all caregivers are assessed—only those whose care recipient goes through the case management system at the AAA.

State officials from IDEA indicated that both the caregiver and the care recipient are considered the client in *Iowa Family Caregiver.* The key informant from I4A believed the family caregiver is the identified client in the program, however.

Aged Medicaid waiver: Eligibility is consistent with federal Medicaid requirements extended to recipients of Supplemental Security Income (SSI) or to those whose income does not exceed 300% of the maximum monthly payment under SSI and 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.

Regarding Iowa's Aged Medicaid waiver, uniform assessment standards exist to determine the level of care required but not to determine each client's service needs. The DHS has adapted the CMS Outcome and Assessment Information Set (OASIS) in this effort. 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. Respondents stated that they assess the family caregiver's needs and ability to provide care only if the care recipient chooses the family member as a care provider.

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

Services

Each AAA in Iowa offers all of the five core NFCSP services to family caregivers, but each provides a different level of service based on its funding allocation under the NFCSP. These services include:

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

Iowa's AAAs are not typically direct service providers, except that each AAA family caregiver specialist does provide some direct services, such as information and referral, public education and maintenance of a resource database. Respondents indicated that most NFCSP funds are used for information and assistance, with other services including respite and supplemental services, (including the provision of legal assistance) and the purchase of emergency response systems. AAAs have the flexibility to meet local needs. In this vein, staff have been creative when trying to assist caregivers. As one example, a farmer was supplied with rechargeable batteries for his walkie-talkie so that he could stay in contact with his wife while he was on the farm.

In the *Iowa Family Caregiver* program, AAAs have the option to provide in-home, adult day services and facility-based respite. Worker and provider shortages—particularly in rural areas—may mean that certain types of respite are unavailable in some areas. Early on, some AAAs chose to cap the amount of funds for respite, but this is no longer practiced. Rather, some AAAs now cap supplemental services, although there is no standard amount across AAAs.

Under the state's Aged Medicaid waiver, respite care for caregivers is provided, including adult day services.[23] Iowa's Aged Medicaid waiver offers in-home, adult day care and facility-based respite, as well as respite camps. Respite provided outside of a consumer's home is limited to 72 continuous hours, however. The waiver has an overall cost cap of $1,052 per month for nursing level of care and $2,480 for skilled level of care. Within this cap is a limit of 14 days of continuous, 24-hour respite.

Major services needed by caregivers: Iowa stakeholders indicated that caregivers needed assistance navigating "the system." Identification of the major service needed varied among state officials. Officials from IDEA cited information and assistance. Medicaid respondents indicated that respite and assistance with physical needs, such as transportation, were the major services needed. Medicaid officials went on to say that "Iowans like to take care of their family and as a result, burn themselves out."

d All of Iowa's six Medicaid waivers include respite care as a service category.

Table 2. Family Caregiver Support Services in Iowa

Program	Iowa Family Caregiver	Aged Medicaid waiver
State Administrative Responsibility	Iowa Department of Elder Affairs	Iowa Department of Human Services
Local Service Delivery	AAAs[a] Local service agencies	AAAs—case management only (under contract with IDEA) Local service agencies
Funding Source	Older Americans Act, Title III-E	Medicaid 1915 (c) waiver
Expenditures FY 2001	$1.4 million[b]	$12.6 million
Client Population	Family & informal caregiver	Care recipient
Eligibility Criteria		
Age	60+ care recipient Family caregivers of any age of persons 60+	65+ care recipient
Income	None	Up to 300% of SSI
Functional Ability	For respite and supplemental services—at least 2 ADLs or cognitive impairment for care recipient	Nursing home level of care for care recipient
Uniform, Statewide Caregiver Assessment	No	No
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite care
Respite Cap	Not required and varies by AAA	Monthly cost cap of $1,052, 14-day cap of 24-hour, continuous respite care
Consumer Direction	Yes; consumers choose from a menu of services and can hire family and friends to provide respite care through a voucher system	Yes; Consumer-Directed Attendant Care component of waiver
Family Caregivers Paid as Respite Providers	Yes	Yes

a AAAs = Area Agencies on Aging.
b Federal funds only.

Consumer Direction

Both *Iowa Family Caregiver* and the Aged Medicaid waiver offer consumer-directed options. With *Iowa Family Caregiver,* consumer direction varies by AAA. The care manager determines the menu of services that would be appropriate for each family caregiver. The family caregiver then decides which services to use to meet his or her needs. If respite care is one of these services, caregivers have the option of hiring family and friends to provide it. There are intentionally no restrictions on who can provide respite, partly because of a lack of providers in Iowa's vast rural areas. Further, respondents indicated that Iowans could be particularly concerned about having "strangers" provide care and generally are more comfortable with family and informal providers.

Under *Iowa Family Caregiver,* family and informal respite providers are paid through a voucher system. This same voucher can be used for other services. One family caregiver had requested transportation reimbursement to take her husband to the doctor, for example. Although she had her own automobile, the battery had died, and she could not afford to replace it. The AAA offered to buy the caregiver a new car battery in lieu of transportation, for which a voucher was provided.

Iowa's Aged Medicaid waiver also includes a consumer-directed element, known as consumer-directed attendant care. This allows the Medicaid recipient to hire a care worker to provide respite and personal assistance services. Providers must conform to the following DHS requirements: (1) must be 18 years of age or older, (2) must be qualified by training or experience to carry out the consumer's plan of care pursuant to the IDEA-approved service plan, (3) must not be the spouse of the care recipient and (4) must not be the recipient of respite services paid through the waiver on behalf of a consumer who receives waiver services. While formal providers, such as adult day health, must have a certificate of formal training, family caregivers do not need this training to serve as providers. A family caregiver who chooses to be a provider cannot receive paid respite care, however.

Quality Assurance and Evaluation

The state does not require, nor does I4A use, a standard intake form or assessment tool. As mentioned previously, the assessment is uniform only when the care recipient is assessed through the formal case management program. In terms of data collection, respondents indicated that they collect "what the [federal government] requires." Although Iowa is moving toward an electronic system, data currently are entered manually. Key informants noted that a new, electronic system will allow them to monitor the program on a quarterly basis, and to track service utilization, clients served and so on. Respondents pointed out that AAA staff vary in level of skill, and AAAs vary in level of technology. Although Iowa is currently collecting data on caregiver outcomes, the state is interested in incorporating the Federal Performance Outcomes Measurement Project (POMP) in the NFCSP.

Under the Aged Medicaid waiver, respondents indicated that "not much" is collected about family caregivers and noted that the only data provided regards the services paid for under the consumer-directed care program (i.e., what has been provided and billed and who the provider is). The DHS has a new computer program for its automated data collection system and is moving toward an outcome-based system of data collection for all Medicaid waivers. Respondents pointed out that data collection is limited to the care recipient—not to the family caregiver—because the "client" of the program is viewed solely as the care recipient.

Systems Development

Respondents characterized their experience implementing the NFCSP in Iowa as largely positive, noting that it has been a vehicle to enhance collaboration and coordination. Further, they commented that it has brought out stakeholders with whom the AAAs had not worked before implementation of the program. Because of the newness of the program, I4A is continuing to refine its programs and services. As an example, it is offering and/or requiring more formal training for each AAA caregiver specialist to ensure a more consistent approach. This would also ensure specific familiarity with *Iowa Family Caregiver* services, rather than with only the AAA's menu of services focusing on the care recipient.

Medicaid officials were not familiar with the NFCSP in Iowa and had no role in developing the program.

Regarding the Aged Medicaid waiver, state officials indicated that services are coordinated at the state level but that service delivery is at the local level. Both Medicaid waiver and *Iowa Family Caregiver* respondents indicated that their programs are integrated into the state's other long-term care programs, because of the state's focus on case management, although Medicaid officials indicated that the integration is only "to some degree."

Iowa does not have a body whose mission is coordination of family caregiver support services across state departments. One stakeholder indicated that IDEA has held some strategic planning sessions with regard to caregiver support. The respondent also indicated that the Senior Living Trust has a coordinating unit, but caregiver support has not been addressed in this context. Officials of the IDEA indicated that *Iowa Family Caregiver* is integrated into the state's other long-term care programs rather than being a stand-alone program.

State Involvement of Family Caregivers in *Olmstead* Decision Planning

In response to the Supreme Court's recent *Olmstead* decision, Iowa's governor identified the DHS as the lead agency in this effort. DHS conducted public meetings and site visits to assist it in developing its *Olmstead* report, submitted in August 2002.[18]

Iowa used to have a specific *Olmstead* task force, but respondents noted that the task force had changed its name in 2002 to the *Olmstead* Real Choices Consumer Task Force. The task force includes representation from IDEA and family members, although not specifically from family caregivers of older persons.

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?" Stakeholder responses varied, with two identifying a "low" level of priority and one identifying a "high" priority. State officials were also mixed, with one respondent stating that there was a "medium" priority, the other a "high" priority.

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

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

1. The one-stop shop approach for *Iowa Family Caregiver*—including a toll-free number and a website providing information on the program
2. Assessment—because family caregivers do not always know what they need
3. Respite care—to give families a break and also peace of mind

When asked to identify the challenges for implementing family caregiver support programs in their state, Iowa respondents noted the following:

- ✧ Public awareness—getting the word out is expensive
- ✧ Service coordination

Major lesson learned: The view of Iowa's respondents is that *Iowa Family Caregiver* has helped move the aging network to broaden its focus on family issues, particularly in helping adult children. The program has also encouraged respondents to relook at the allocation of resources. Although the state had been moving in that direction, key informants indicated that it has been easier with the resources and tools that the NFCSP has provided. In terms of this paradigm shift, one key informant characterized the NFCSP as an "awakening."

Other state officials from the Aged Medicaid waiver program discussed the struggle between providing flexibility and ensuring oversight. They also pointed out the difficulty in defining quality, especially in consistency between consumer and provider perceptions of quality. Finally, respondents indicated that providing caregiver support is a balancing act.

State officials also commented the waiver could support family caregivers even more if Medicaid law were changed to allow spouses or parents of minor children to be paid providers of care. The officials pointed out that "it is less expensive and [these family members] do a better job."

Opportunity for expanding caregiver support: All Iowa respondents indicated that new initiatives or expansion of state-funded programs to support and strengthen family caregivers over the next three to five years would depend on the budget situation. One key informant indicated that the current emphasis in Iowa is on programs that receive federal matching funds, rather than only state general funds.

Recommendations for other states: Respondents made a variety of recommendations:

- Being flexible and encourage the development of partnerships and collaborations.
- "Build support in your state…so when the time comes [to start up new programs] there is not strong opposition."
- Meet the needs of older persons and their families.

NOTES

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