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

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By

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O V E R V I E W

Indiana is a moderately sized midwestern state, characterized by a relatively homogenous and increasing rural population. The state’s current long-term care system has been recognized for its innovation and for its significant state funding for home and community-based services. Although programs are decentralized, with a single point of entry at the local level and consolidated administration at the state level, frequent reorganizations, programmatic shifts and significant budget shortfalls have challenged this approach.

Some state policy attention to caregiver support services has existed since 1987, although focused attention on this population has emerged only recently, with the passage of the National Family Caregiver Support Program (NFCSP) and the infusion of federal funds into Indiana’s state budget. The state’s developing caregiver support services are characterized by:

- Integrated programs and services, with a single point of entry
- A statewide logo and tag line to promote a consistent, statewide identity for the program
- A decentralized approach to service delivery, with statewide standards

Indiana respondents noted that the major service needs of family caregivers are (1) respite care, (2) information and ongoing support, (3) emergency services and (4) support groups.

I N T R O D U C T I O N

Indiana represents a “new” state in this study. Specific caregiver support programs were not in place prior to the passage of the NFCSP. The project team conducted a site visit on May 21 and 22, 2002, interviewing government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Family and Social Services Administration, Division of Disability, Aging and Rehabilitative Services
- Family Caregiver Support Program (NFCSP funded)
- Community and Home Options to Institutional Care for the Elderly and Persons with Disabilities (CHOICE) program (state funded)
- Aged/Disabled Medicaid waiver

Stakeholders interviewed were from
- Indiana Association of Area Agencies on Aging
- Alzheimer’s Association, Central Indiana Chapter

Three programs are featured:
1. Family Caregiver Support Program
2. CHOICE
3. Aged/Disabled Medicaid waiver
BACKGROUND

Indiana is a midsized midwestern state with a population of 6.1 million people who reside in 92 counties. Nearly two-thirds of the state’s residents live in urban areas (64.9% in 1990).\(^1\) Recent growth has occurred disproportionately in rural areas, however, reflecting a long-term pattern of suburbanization that many feel threatens the economic and social viability of both communities and rural areas.\(^2\)

In 2000, personal income per capita was $27,011, lower than the national average of $29,676.\(^3\) About 10% of Indiana’s population live below the federal poverty level (vs. 13.3% U.S.).\(^4\) Indiana ranks 32\(^{nd}\) nationally in percentage of households with Internet access.\(^5\) The racial makeup of the state’s population differs somewhat from that of the United States as a whole, with Indiana having a smaller proportion of both African American (8.4% vs. 12.3% U.S.) and Hispanic (3.5% vs. 12.5% U.S.) persons\(^6\) (table 1).

An estimated 988,506 persons in Indiana were 60 years or older in 2000, with Indiana having the same proportion of older persons as the nation as a whole (16.3%). Indiana ranks 29\(^{th}\) nationally in the number of older persons (ages 60+) residing in the state.\(^7\) Similar to the state’s population as a whole and compared to the national average, Indiana has a smaller proportion of African American (5.9% vs. 8.4% U.S.) and Hispanic (1.1% vs. 5.4% U.S.) persons ages 60+.\(^8\) Indiana ranks 28\(^{th}\) nationally in the proportion of its population ages 85 and older. In 2000, 91,558 persons, or 1.5% of Indiana’s population, were ages 85+.\(^9\)

An estimated 568,307 family caregivers reside in Indiana. These family caregivers provide about 529 million hours of caregiving per year at an estimated value in 1997 of $4.3 billion.\(^10\)

With a state tax revenue in 2001 of $10.2 billion, or $1,669 per capita, Indiana ranks 38\(^{th}\) among all of the states. As a share of personal income, total state taxes dropped from 6.5 % in 2000 to 6% in 2001.\(^11\) Key informants noted that Indiana had a budget surplus two years prior and, like many other states, had instituted a number of tax cuts and, “permanent give-backs, which evaporated the budget.” Projections of tax growth then were not based on good numbers, informants reported. Since then, 100,000 jobs have been lost in the state. Indiana’s constitution requires a balanced budget, so programs must be cut if tax revenues are insufficient.
Table 1. Selected Characteristics of INDIANA and the UNITED STATES, 2000

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Indiana</th>
<th>United States</th>
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</thead>
<tbody>
<tr>
<td><strong>Total Population Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Pop.</td>
<td>6,080,485</td>
<td>281,421,906</td>
</tr>
<tr>
<td>% African American</td>
<td>8.4%</td>
<td>12.3%</td>
</tr>
<tr>
<td>% Hispanic</td>
<td>3.5%</td>
<td>12.5%</td>
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<tr>
<td><strong>Older Population Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pop. 60+</td>
<td>988,506</td>
<td>45,797,200</td>
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<tr>
<td>% 60+</td>
<td>16.3%</td>
<td>16.3%</td>
</tr>
<tr>
<td>National ranking 60+</td>
<td>29</td>
<td>NA</td>
</tr>
<tr>
<td>Pop. 65+</td>
<td>752,831</td>
<td>34,991,753</td>
</tr>
<tr>
<td>% 65+</td>
<td>12.4%</td>
<td>12.4%</td>
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<tr>
<td>National ranking 65+</td>
<td>28</td>
<td>NA</td>
</tr>
<tr>
<td>Pop. 85+</td>
<td>91,558</td>
<td>4,239,587</td>
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<tr>
<td>% 85+</td>
<td>1.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>National ranking 85+</td>
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<td>NA</td>
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<tr>
<td>% increase 1990–2000 60+ pop.</td>
<td>5.3%</td>
<td>9.4%</td>
</tr>
<tr>
<td>% White (60+)</td>
<td>92.0%</td>
<td>82.4%</td>
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<tr>
<td>% African American (60+)</td>
<td>5.9%</td>
<td>8.4%</td>
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<tr>
<td>% Hispanic (60+)</td>
<td>1.1%</td>
<td>5.4%</td>
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<tr>
<td>% Asian (60+)</td>
<td>0.4%</td>
<td>2.5%</td>
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<tr>
<td>% Native Hawaiian/Pacific Islanders (60+)</td>
<td>0.0%</td>
<td>0.1%</td>
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<tr>
<td>% Amer. Indian/Alaska Native (60+)</td>
<td>0.1%</td>
<td>0.4%</td>
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<tr>
<td><strong>Informal Caregiver Characteristics</strong></td>
<td></td>
<td></td>
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<tr>
<td># of caregivers (1997)</td>
<td>568,307</td>
<td>25,798,370</td>
</tr>
<tr>
<td>Caregiving hours (millions) (1997)</td>
<td>529.0</td>
<td>24,013.1</td>
</tr>
<tr>
<td>Value of caregiving (millions) (1997)</td>
<td>$4,327.1</td>
<td>$196,426.7</td>
</tr>
<tr>
<td><strong>Economic Characteristics</strong></td>
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<td></td>
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<tr>
<td>Per capita income</td>
<td>$27,011</td>
<td>$29,676</td>
</tr>
<tr>
<td>% of pop. below poverty (1997)</td>
<td>9.9%</td>
<td>13.3%</td>
</tr>
<tr>
<td><strong>Internet</strong></td>
<td></td>
<td></td>
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<tr>
<td>% of households w/Internet access (2001)</td>
<td>39.4%</td>
<td>41.5%</td>
</tr>
<tr>
<td>Nat’l ranking of households w/Internet access</td>
<td>32</td>
<td>NA</td>
</tr>
</tbody>
</table>

a Unless otherwise noted, all data are from 2000.  
c Ibid.  
d Ibid.
The DDARS coordinates other community-based and protective services, including congregate meals, information and referral, legal services, ombudsman, preventive health services, adult protective services, adult guardianship, senior employment, nursing home preadmission screening and annual resident review, the residential care assistance program and money management and representative payee programs.\(^\text{12}\) The BAIHS administers the statewide IN-Home Services program, which was implemented in July 1992. This is Indiana’s case management system, which brings together funding from several sources to provide an integrated, single point of entry for consumers at the Area Agency on Aging (AAA) level. In addition, Indiana’s aging network includes a statewide system of 16 AAAs, all nonprofit organizations. The areas covered by the individual AAAs range from two to nine counties: Two of the AAAs are affiliated with private universities. The DDARS contracts with the AAAs to administer funds for the state-funded CHOICE program as well as for the IN-Home Services case management system. Persons of all ages with disabilities may access services through the
AAAs. The AAAs’ local administrative functions, in addition to case management, include budgeting, oversight, monitoring, quality assurance and submission of fiscal claims to the DDARS. The AAAs arrange for individually needed services through subcontracts with local vendors and rarely provide direct services themselves. If no other agency is available to provide a specific service, however, the AAA may be granted a waiver from DDARS to deliver that service.

The FSSA serves as the “single state agency” for Medicaid, and its Office of Medicaid Policy and Planning has oversight responsibility for the day-to-day operations of Indiana’s Medicaid program. Administration of the Medicaid waivers, however, is through the BAIHS, rather than through the Office of Medicaid Policy and Planning. Persons desiring Medicaid waiver services can apply at any of many different local offices statewide, including AAAs, Vocational Rehabilitation, Bureau of Developmental Disabilities Services and the Division of Family and Children.

Original approval for the Aged/Disabled Medicaid waiver occurred in 1984. In FY 2001, with the original federally approved level of 2,500 slots still in effect, 2,352 individuals were served under this waiver. Indiana has made a major change in its Medicaid strategy in the recent past, maximizing Medicaid reimbursement by moving clients from the state-funded program to Medicaid. The state has now received federal approval for an additional 10,000 slots, bringing the total to 12,500 for FY 2003. Because the state legislature must also approve the expansion, not all additional spots have been filled, however. The legislature approved 822 new slots for FY 2002 and another 813 for FY 2003. A significant gap will soon exist between the number of waiver slots authorized by the federal government and the number authorized by the state, which holds implications for Olmstead-related planning and implementation.

In 2002, Indiana received nearly $1.4 million through the Centers for Medicare and Medicaid Services (CMS) Real Choice Systems Change grant. The grant was awarded to the FSSA with the goals of (1) creating an enduring, system-wide infrastructure to support consumer-directed community-based supports and services, (2) involving all relevant state agencies and private partners, (3) continuing education and information for and from older adults and persons with disabilities and their families or caregivers about options and barriers in the system of community supports and services, (4) assisting consumers in recruiting and training providers, (5) expanding the services and supports available through consumer direction, (6) ensuring that consumers are safe and are not abandoned when they have problems with services and supports, (7) monitoring changes taking place and (8) evaluating changes in services and supports in order to replicate when appropriate and to ensure that desired changes are integrated into the perceptions and actions of all communities.

\[a\] Indiana has implemented seven Home and Community-Based Medicaid waivers: Aged/Disabled, Autism, Developmental Disabilities, Medically Fragile Children, Traumatic Brain Injury, Assisted Living and Support Services.
OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Indiana has a long history of innovation and support for community-based long-term care. In 1998, the National Governors Association recognized Indiana for giving care managers the authority to blend funds for home care services and for decentralizing power across the state’s 16 AAAs.17

Indiana’s home and community-based services to families and their caregivers are provided through the IN-Home Services program. Programs and funding sources include the new NFCSP, CHOICE, the Aged/Disabled Medicaid waiver, Social Services Block Grant (SSBG) funds, an Alzheimer’s Disease Demonstration Grant to States funded by the U.S. Administration on Aging and a CMS Real Choice Systems Change grant.

The CHOICE program is Indiana’s only program providing services to family and informal caregivers that is exclusively state funded. The CHOICE program, providing home and community-based services to older persons and to persons with disabilities, was enacted as a pilot program in 1987 and expanded statewide in 1992. The program has received national recognition and is popular with state legislators, a number of whom have themselves used CHOICE for their family members. Indiana’s governor appoints a board to govern the program.

SSBG has also provided funding for home and community-based services, which has been allocated to the DDARS since 1992. These monies pay for a portion of respite care, adult day health services, attendant care, transportation, home-delivered meals, homemaker services, home health services and supplies. In FY 2001, 46,704 persons in Indiana received assistance through SSBG-funded services.

Indiana’s Governor’s Task Force on Alzheimer’s Disease and Related Senile Dementia was established in 1987. This task force assists the DDARS “by identifying areas of concern to be addressed, recommending services to meet the needs, recommending the development of training materials, and compiling available research.”18 Five grants, totaling $83,894, were awarded in FY 2001 to meet the needs of individuals with Alzheimer’s or a related condition and their families.

When asked if family caregivers were a central component of a comprehensive long-term care system, Indiana state officials uniformly responded that family caregivers are increasingly being recognized in this capacity. To support this notion, respondents cited evidence of this recognition: legislation passed in 2001, the CHOICE enabling legislation b and questions about informal support in the state’s E-Screen, the instrument used for assessment for waiver and CHOICE services, as well as for nursing home preadmission screening. The legislation creating CHOICE was the state’s first legislation to mention caregivers explicitly. The bill also established the Governor’s Commission on Caregivers. This commission was focused on workforce shortage issues associated with formal caregivers, however, rather than on supporting family and informal caregivers. Respondents also pointed to other legislation, passed in 2001, that allows recipients of CHOICE and Medicaid waiver services to direct their attendant care services workers (with the written approval of the attending physician), enabling certain family members to be hired as attendants. c Although Indiana does not yet have a caregiver tax credit, the state’s Department of Revenue was reported to be working on it.

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b CHOICE was created through Senate Enrolled Act 215 in 1987.
c Parents of minors, spouses or other adults legally responsible for the individual may not be compensated, however.
Within all of the state’s long-term care programs, the priority for supporting caregivers was seen to be growing, one informant said that support for caregivers was particularly important “especially if we want to move people into the community or keep people in the community.” One respondent noted a small shift, for the first time, toward more support for community-based long-term care. According to one respondent, nursing home funding has been “in a different pot and has been fairly unassailable.”

Stakeholders in Indiana did not believe that family caregivers were receiving much state recognition. As one pointed out, “In terms of getting state dollars, programs in place, we’re just trying to make it on the radar screen.” Another said that research is needed to educate legislators about the caregiver’s role and needs. The state’s focus, they believed, is still primarily on the care recipient, which they ascribed to the notion that “the patient seems needier.” Stakeholders noted hope in two developments for family caregivers, however. First, in 2002, the legislature passed a concurrent study resolution that directs the legislature to set up a study committee to look at rebalancing Indiana’s long-term care systems. Explicit emphases for this study include enabling more people to stay in their own homes, under the care of their families, and providing family caregivers with governmental assistance for their “medical, financial and emotional support.”19 Second, the governor has proclaimed November to be Caregiver Month.

Key informants saw a number of strengths in Indiana’s current caregiver support system. These include flexibility through NFCSP funding, the cooperation across departments to look at caregiving issues and the flexibility offered through Indiana’s newest Medicaid waiver, Support Services (administered by the Bureau of Developmental Disability Services), which includes a “family subsidy,” with funds going directly to the family to purchase what they need, as well as training for informal and family caregivers (with a limit of $2,000 per person annually). One respondent saw Indiana’s “blank slate” as a strength. In terms of building caregiver support services into existing infrastructures, respondents pointed to the addition of consumer-directed care to every Medicaid waiver program and to the addition of family and caregiver training to the waivers.

Program Background/Development

The only program specifically for family caregivers in Indiana is the new NFCSP. Because all community-based long-term care programs (including NFCSP) are integrated and delivered through the AAAs, however, it is important to understand the operations of all three main programs in order to understand the support available to Indiana’s family caregivers. These programs are CHOICE, the Aged/Disabled Medicaid waiver and the NFCSP.

NFCSP: After receiving notification from the Administration on Aging (AoA) that NFSCP funding would be available, the BAIHS asked the AAAs to include goals and indicators for the new program in their area plans for July 1, 2001, to June 30, 2002. The AAAs worked collectively on publicity and outreach, pooling funds to develop a statewide caregiver campaign. The Indiana Association for Area Agencies on Aging (I4A) and an advertising agency assisted with the effort. They developed four radio commercials, three television commercials and a brochure, all featuring the same logo and tag line (“Compassion. Connections. Care. Area Agencies on Aging/Partners of the Indiana Caregivers Alliance”) to promote a consistent, statewide identity. The advertising agency also conducted a public relations workshop for the AAAs and helped them contact their local media to place their public service announcements (PSAs). Additionally, a statewide toll-free telephone number connects automatically into the caller’s local AAA or if the caller is out of state, the Indianapolis AAA.
The AAAs have been slowly implementing their plans, with one having just begun in March 2002. Each of the AAAs has a designated “caregiver coordinator,” who may be a member of the information and referral (I&R) staff, a case manager, a community outreach worker (as in one case) or the AAA director (as in another). Calls from caregivers are directed to the coordinator. Respondents indicated that coordinators try to balance the needs of new callers with those of caregivers whose loved one is already on a waiting list for CHOICE or Medicaid waiver services. (The wait for CHOICE is up to three years.) Each AAA has oriented its provider network to the NFCSP services and eligibility criteria in an effort to achieve a “mind shift” about who the client may be (i.e., the caregiver, not the care recipient).

At the time of the site visit, standardized products had not been developed, but the care coordinators, meeting as a group, were working on this. They had developed a Family Caregiver Referral Form for use by all AAAs, had drafted a memorandum on billing issues and were trying to get caregiver information included in IN-Site, the automated data collection and reporting system. The care coordinators were reported to be doing a lot of policy development and networking with one another. Two or three AAAs were working with the BAIHS to develop a cost-sharing method for services, such as transportation, as had been done in North Carolina and Ohio.

At the state level, the BAIHS looked to North Carolina, Ohio, Pennsylvania and California in developing its approach. The BAIHS worked closely with I4A to launch the program. In December 2001, the BAIHS spelled out its expectations in a memorandum to the AAAs, including reporting units of service in line with the BAIHS operations manual. Family caregivers have been, and will continue to be, involved through AAA advisory committees and through the area plan development process. The state intends to spotlight the program and the AAAs’ efforts at the October 2002 Governor’s Conference. There have been state press releases and local public relations activities, including AAA involvement in county fairs and with local Alzheimer’s Association chapters.

**CHOICE:** The CHOICE program pilot, approved by the state legislature in 1987, expanded statewide in 1992. The program was designed to serve people who did not meet Medicaid eligibility criteria (particularly financial criteria). With the state’s recent effort to maximize Medicaid revenue, there has been a concomitant effort to transfer CHOICE recipients who qualify for Medicaid to the Aged/Disabled Medicaid waiver program. Many do not wish to be transferred, however.

**Aged/Disabled Medicaid waiver:** Original approval for this waiver occurred in 1984.

**Most rewarding:** Respondents indicated that the NFCSP provides Indiana with another option, with a lot more flexibility than the Aged/Disabled Medicaid waiver, saying, “It allows us to address the waiting list for CHOICE and Medicaid.” It also allows those with limited need to be reached.

Regarding the CHOICE program, one key informant indicated that the program “has become a rallying cry.” It is a “very good, very popular program which has had good press” and brought people into the AAAs, the respondent said. The individual who needs service is not required to apply for Medicaid. CHOICE is “a lifeline for many to remain in their own homes.”
Biggest challenge: The newness of the program and the activities necessary to “get settled” and “up and running,” including to develop public awareness, have been particularly challenging. Respondents indicated that funding and waiting list size are among the CHOICE program’s biggest challenges. During the past fiscal year, a budget increase was slated for CHOICE. Because of the state’s fiscal situation, however, some of these funds were “reverted” or given back to the state. One stakeholder explained that the money being saved as consumers are transferred from CHOICE to Medicaid waiver status is going back into the state general fund to help offset the tax deficit, rather than to enable CHOICE to serve people now on the waiting list. Another noted that state staff have been focused on the state’s fiscal constraints: No one is dedicated to developing new programs under the present circumstances.

FUNDING

In FY 2001, the first year of federal funding under the NFCSP, Indiana received $2.3 million in federal funds. In FY 2002, the federal share of the NFCSP increased to $2.6 million. State officials did not provide the proportion of NFCSP funds to the total BAIHS budget.

In FY 2001, 12,537 individuals were served through CHOICE, while an additional 11,922 persons were on the waiting list to receive services. State officials did not provide the expenditures through the Aged/Disabled Medicaid waiver in FY 2001–02, or for the CHOICE program.

The average annual expenditure per person in CHOICE in FY 2001 was $7,234. The average monthly expenditure through CHOICE is about 71% of that through the Aged/Disabled Medicaid waiver ($603 vs. $848).

Indiana received about $141 million in tobacco settlement revenues in FY 2001 and another $170 million in FY 2002. Indiana’s tobacco settlement fund utilization was in flux at the time of the site visit. Prior to the budget crisis, the state had earmarked all of its tobacco funds for health purposes, including the creation of Hoosier Rx (a prescription drug program for older residents) and a new appropriation for services targeting individuals with developmental disabilities. In light of current revenue shortfalls, “reversion” of the tobacco funds was under way. A Medicaid 1115 waiver request reported to be under development would have also made use of the tobacco funds for the required state match, but this new appropriation of $20 million was apparently going to be used for other state budget purposes.

The impact of the downturn in the economy on services to support family caregivers remains unknown. “There is a great effort within FSSA to not cut programs,” one respondent said. “So far there have been no cuts in services. Moving clients from state general fund programs to Medicaid or other federal programs has been the strategy.” Cuts in CHOICE were seen as likely if no new revenue could be found, however.

The state budget situation was described variously as “pretty bad,” “tight,” “very challenging” and “dismal.” Revenues had been down three successive quarters, and recovery was expected to take three years, even if revenues improved immediately. Whereas Indiana had previously projected excessive growth, state officials now expect a “no-growth” period to predominate for the next several years. State employees had not received raises for three years, and all agencies had been asked to make cuts.
One respondent reported that CHOICE had been cut, the expansion of the Medicaid waiver pro-
gram had slowed and plans were under way to divert people eligible for nursing homes into home
and community-based services (without adding funds to those services). A strong nursing home
lobby exists in Indiana, and nursing home operators have sued the state on various issues; these suits
were expected to cost millions of dollars, further depleting the resources available for home and
community-based services.

**PROGRAM ADMINISTRATION**

*NFCSP:* In Indiana, services are viewed as separate components, rather than as part of a larger,
multicomponent family caregiver support program. The BAIHS sees its role in administering the
NFCSP as one of overseeing and encouraging flexibility. Respondents indicated that the AAAs have
the flexibility to do anything, so long as it is in the plan of care. AAAs can provide any or all of the
five NFCSP service categories in any combination. The caregiver support program is administered at
the local (AAA) level through contracts.

Policies for caregiver services are being developed using a very broad framework. Care coordinators can
run questions by the state, but they are encouraged to use their flexibility. Comparing the NFCSP to
the Medicaid waiver, one key informant observed, “This program is much easier to administer.”

The state’s role in policy development is to encourage consistency across the state. For that reason,
accreditation of the AAAs is being pursued through the National Council on Accreditation for
Children and Family Services, which is developing Indiana-specific standards. By 2006, all AAAs are
expected to be accredited.

*CHOICE:* The program is administered locally through the AAAs. The state uses the Title III formula
to allocate the CHOICE budget. AAAs have memoranda of understanding with providers and AAA
staff to do assessments, arrange for services and pay bills. They also act as the fiscal intermediary, or
they contract for fiscal intermediary services for consumers who wish to be the employer of record.
Each AAA must submit to the DDARS a CHOICE Plan as a component of the area plan. Policies for
CHOICE are reviewed by BAIHS staff, with AAA input, then reviewed by the CHOICE board.

*Aged/Disabled Medicaid waiver:* AAAs administer the program locally. AAA’s role for Medicaid waivers
is similar to its role for CHOICE, except that the fiscal intermediary, EDS, pays the bills. The waiver
and CHOICE look similar to consumers, but not to providers.

Both the legislature and CMS must approve any substantive policy changes for the Aged/Disabled
Medicaid waiver. For example, CMS approved consumer-directed service after the Indiana legislature
enacted legislation allowing this.
**Program Eligibility/Assessment Process**

**NFCSP:** Indiana’s NFCSP uses AoA eligibility guidelines. Both the care recipient and the caregiver are considered the client, however. Currently, information about the caregiver is captured through case notes in IN-Site; work is under way to develop specific questions for inclusion. The case notes can be “data mined.” Presently no uniform assessment standards for caregiver need are in use across the state.

Caregiver coordinators do not create care plans like the ones that care managers for CHOICE and Medicaid waiver do, but they are using the Family Caregiver Referral Form and are working to gain the cooperation of I&R staff in using this form. The I&R staff reported that they were not yet getting all of the right information.

**CHOICE:** To be eligible for CHOICE, an individual must be a resident of Indiana, ages 60 or older or any age with disabilities, and unable to perform two or more Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs). The number of ADL deficits required to receive services through CHOICE has changed over time, from two to one and now back to two again. That determination is made using the Long Term Care Services Eligibility Screen (E-Screen).

There are no financial eligibility criteria for CHOICE, but income determines share of cost, using a sliding scale. Eligibility for the sliding scale starts at incomes less than 350% of poverty. The cost-share formula is designed to protect an individual’s monthly income (after paying for CHOICE services) from falling below 151% of poverty. Persons paying privately are not responsible for the cost of case management, the initial assessment and the care plan.

The care recipient, rather than the family caregiver, is considered the client in CHOICE. At least 20% of the AAA’s CHOICE service dollars must be used for persons under the age of 60 with disabilities. The CHOICE program also taps Temporary Assistance to Needy Families funds on behalf of children under the age of 18, providing up to $2,000 per year for these clients for family caregivers to participate in support groups or obtain educational materials.

The state’s role in policy development is to encourage consistency across the state. Uniform assessment standards are used across Indiana for CHOICE, and these are incorporated in the E-Screen. The care manager records informal care, which affects what is included in the care plan. The family caregiver’s needs and ability to provide care are assessed informally, as a “judgment call” by the assessor, and recorded in case notes.

**Aged/Disabled Medicaid waiver:** The E-screen is also used to assess eligibility for the Medicaid waiver. Beneficiaries must have difficulty with at least three ADLs or IADLs. They also must be categorically needy or have countable incomes at or below 300% of Supplemental Security Income (SSI), with assets not to exceed $1,500.
SERVICES

NFCSP: Under the NFCSP, services are delivered locally. All five of the permissible NFCSP service components are being provided in the state, although not necessarily by each AAA. They are:

1. Information to caregivers about available services (all AAAs)
2. Assistance to caregivers in gaining access to supportive services (all AAAs)
3. Individual counseling, organization of support groups and caregiver training to assist caregivers in making decisions and solving problems related to their caregiving roles (some AAAs)
4. Respite care to temporarily relieve caregivers from their caregiving responsibilities (all AAAs)
5. Supplemental services, on a limited basis, to complement the care provided by caregivers (some AAAs)

AAAs’ care coordinators generally arrange for respite care, referring caregivers to support groups (and sometimes developing and facilitating such groups) and providing education and training. Respondents reported that the Fort Wayne AAA had set up an information session for caregivers at a major employer’s location and found, to its surprise, that 90% of those who showed up were men. This session led to the development of an ongoing support group.

AAAs have the flexibility to offer various types of respite, including in-home care, adult day services and overnight in a facility. No cap is being used for respite, nor are AAAs yet allowing caregivers to “bank” respite benefits. One AAA is piloting the use of respite vouchers that family caregivers can use to attend support group meetings.

CHOICE: Services that support family caregivers through CHOICE are seen as part of a multicomponent program. Among caregiver support services that may be included in a CHOICE care plan are respite care, “other services” (including home modifications or adaptive aids) and training.

There are no caps on respite, per se. Respite services may be delivered in the home, in adult day care, overnight in a facility and on a weekend—but not through camps. Respite benefits may be “banked” and used whenever needed, except that the dollar limit for the quarterly care plan may not be exceeded within CHOICE. Case management is considered an AAA administrative function and is excluded from the calculation of cost. With limited funding, the total care plan has a maximum.

There is no cap for any service provided through CHOICE, except for the total care plan guidelines tied to the CMS skilled nursing facility index. The program has implemented a system of cost-sharing. A former expenditure cap of around $5,000 per individual per year no longer exists.

Aged/Disabled Medicaid waiver: Caregiver support services through the Medicaid waiver are seen as part of a multicomponent program. Services include respite care, home modifications and reimbursement for adaptive devices. Several forms of respite are provided, including in-home care, adult day care and overnight and weekends in a facility—but not camps.

As in CHOICE, respite is not capped, per se. Respite benefits may be “banked” and used whenever needed.
Access to some services, such as home modification, is difficult to obtain in rural areas. Respondents believed that access to providers is easier for CHOICE recipients than for Medicaid recipients because reimbursement is better and faster and paperwork requirements are less onerous.

Although reimbursement rate limits exist for particular Medicaid waiver services, there is no cap for any service provided through the Aged and Disabled Medicaid waiver, except for the total care plan guidelines tied to the CMS skilled nursing facility index.

Extensive waiting lists exist for CHOICE and Medicaid waiver services. The passage of the NFCSP has not changed the waiting list for either CHOICE or the waiver, although it has enabled some family caregivers to obtain limited services for a relative on a waiting list. Respondents believed that the scope of services provided in CHOICE and in the Medicaid waiver was sufficient. The issue was waiting lists, not range of services offered.

Major service needed by caregivers: Most respondents believed that respite was the major service needed by family caregivers. One stakeholder saw information and ongoing support through the course of the disease as most important and indicated that ongoing support included education, emotional support, in-depth guidance and direction (consultation) and support groups. One respondent said “What caregivers think they want is respite, but after that they want information.” Another informant, a family caregiver who first self-identified as such during the site visit, observed that working caregivers need help to keep their jobs while fulfilling caregiving responsibilities. Other needs cited were emergency services and support groups for grandparents raising grandchildren.
### Table 2. Family Caregiver Support Services in Indiana

<table>
<thead>
<tr>
<th>Program</th>
<th>Family Caregiver Support Program</th>
<th>CHOICE</th>
<th>Aged/Disabled Medicaid Waiver</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>State Administrative Responsibility</strong></td>
<td>FSSA’s Bureau of Aging and In-Home Services</td>
<td>FSSA’s Bureau of Aging and In-Home Services</td>
<td></td>
</tr>
<tr>
<td><strong>Local Service Delivery</strong></td>
<td>AAAs—information, assistance, assessment &amp; case management</td>
<td>AAAs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Service providers/contractors</td>
<td>Service providers/contractors; AAA may get waiver also to provide specific services if no other agency is available</td>
<td></td>
</tr>
<tr>
<td><strong>Funding Source</strong></td>
<td>Older Americans Act, Title III-E</td>
<td>State general funds</td>
<td>Medicaid 1915 (c) waiver</td>
</tr>
<tr>
<td><strong>Expenditures FY 2001</strong></td>
<td>$2.3 million</td>
<td>$38.8 million</td>
<td>$23.9 million</td>
</tr>
<tr>
<td><strong>Client Population</strong></td>
<td>Family &amp; informal caregiver</td>
<td>Care recipient</td>
<td>Care recipient</td>
</tr>
<tr>
<td><strong>Eligibility Criteria:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>60+ care recipient</td>
<td>All ages</td>
<td>All ages</td>
</tr>
<tr>
<td></td>
<td>Family caregivers of persons age 60+</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td>None</td>
<td>None</td>
<td>SSI level; $1,500 in assets</td>
</tr>
<tr>
<td><strong>Functional Ability</strong></td>
<td>For respite &amp; supplemental services, care recipient must have at least 2 ADLs or cognitive impairment</td>
<td>2+ ADLs/IADLs</td>
<td>3+ ADLs/IADLs</td>
</tr>
<tr>
<td><strong>Uniform, Statewide Caregiver Assessment</strong></td>
<td>No</td>
<td>No; uniform care recipient assessment only with limited information on caregiver</td>
<td>No; uniform care recipient assessment only with limited information on caregiver</td>
</tr>
<tr>
<td><strong>Service Provided to Family Caregivers</strong></td>
<td>Information, Assistance, Counseling, support groups, training</td>
<td>Respite, home modifications</td>
<td>Respite, home modifications, adaptive aids and devices</td>
</tr>
<tr>
<td></td>
<td>Respite care</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Supplemental services (e.g., consumable supplies)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respite Cap</strong></td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Consumer Direction</strong></td>
<td>No</td>
<td>Pilot project only</td>
<td>No</td>
</tr>
<tr>
<td><strong>Family Caregivers Paid as Respite Providers</strong></td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

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*b* Ibid, 6. Total is estimated based on average per person per month cost of $848.08 and enrollment of 2,342.

*c* All services provided in Indiana; each AAA does not offer all services, however.
CONSUMER DIRECTION

Indiana's CHOICE program has had a pilot program to provide consumer-directed attendant care for two years. (Parents, spouses and legally responsible adults are not eligible to provide attendant care.) New state legislation provides for a registry, criminal background checks and delivery of services beyond attendant care by a worker, if the physician states, in writing, that the care recipient is competent to manage this care and that the care is safe. At the time of the site visit, 250 to 300 CHOICE clients were using the consumer-directed option.

The pilot came about through the advocacy of clients. Ironically, one chief advocate, a mother of two medically fragile children, had been unable to use this option herself because the care recipient must be capable of hiring, firing and giving instructions to the worker as well as have a backup worker in place. Difficulty in making a backup arrangement was cited as a barrier to use of the option, although a client can have both provider-delivered and consumer-directed care simultaneously—that is, can hire one care provider directly and use an agency provider for the backup.

While the Aged/Disabled Medicaid waiver does not have a consumer-directed attendant care component, both the waiver and CHOICE have other consumer-directed elements. Care recipients in both programs can hire and fire their own workers and can choose from a list of providers for respite care and other services, such as transportation. Parents and spouses are not eligible for reimbursement, however.

Respondents indicated that further implementation of the consumer-directed option had been slowed due to interpretation of the fiscal intermediary provision. The AAAs received training from the Internal Revenue Service about the use of a fiscal intermediary so that the AAA would not be considered the employer. Some clients have contended, however, that the state legislation allows “anyone who is qualified” to be able to act as an intermediary, whereas the state has sought to select a fixed set of people from which a client could choose.

A consumer-directed option is not available in the NFCSP, so that the option can first be refined in CHOICE and the Medicaid waiver. Other than the respite voucher pilot, no direct payments to family caregivers are being made.

QUALITY ASSURANCE AND EVALUATION

AAA staff collect data about family caregivers of persons seeking CHOICE or Medicaid waiver services through informal electronic case notes in the E-Screen. A strength of the state's current data collection practices is the systematic collection of some information, including billing codes and progress notes. Respite units could thus be pulled out and tracked if desired.

Respondents noted limitations of their data collection practices as difficulties in aggregating data and lack of a specific caregiver assessment. Outcomes data are collected only anecdotally through case notes. The E-Screen focuses on the care recipient and includes just three yes/no statements related to informal support. These are:

1. The person has no friends or relatives who are able or willing to provide needed assistance, support, and personal or chore services.
2. Friends or relatives who have been providing needed assistance are no longer able or willing to continue to provide help.
3. Friends or relatives who have been providing needed assistance are not able or willing to increase the amount of help needed to meet changing conditions.

The E-Screen also provides a space for the case manager to summarize the Preliminary Care Plan and prompts the assessor to include “informal supports and other service arrangements.”

To supplement the information collected through the E-Screen, the AAAs have designed a Family Caregiver Program Referral form that collects the following information:

- Date and referral source
- Primary caregiver information (county, name, address, telephone number, Social Security number, birth date, age)
- Care recipient information (name, address, age, birth date, income, relationship to caregiver, length of time caregiver has been caring, diagnosis)
- Hospital or nursing home discharge date
- Constraints on primary caregiver (poor health/frail, employed, lacks knowledge/skills, lives at a distance, financial strain, lacks support system, poor relationship with consumer, providing care to others as well, experiencing emotional concerns, other)
- Obstacles to caregiving (ramp, stairs, no washer/dryer, location, supplies)
- Service requested
- Monthly caregiver supplies (item, average monthly cost, who pays)

To evaluate program success, the state monitors service utilization through IN-Site, makes site visits to the AAAs and home visits to clients and does satisfaction surveys. AAAs must survey 5 to 10% of their in-home services clients. The satisfaction survey was designed under a Robert Wood Johnson Foundation grant as a mechanism to provide regular, anonymous feedback to vendors every six months. If a client reports a problem with health, safety or exploitation, an investigation must be completed under the state’s Quality Assurance Improvement Program.

Over time, the FSSA’s new Bureau of Quality Improvement Services will expand its focus to include other programs, although it is working now only with the Developmental Disability system. Outcome measures are not now used to evaluate the program, mainly because of data set problems. Although the state would like to look at the impact of the CHOICE program on nursing home utilization, that effort has been hampered by the fact that institutional and community-based programs use different data sets. A coalition of five AAAs is looking at caregiver outcomes, with the goal of highlighting these at the October 2002 Governor’s Conference. Cost-effectiveness comparisons with nursing homes are done for CHOICE and the Medicaid waivers. Finally, BAIHS’s Program Evaluation and Accreditation Unit plans to look at CHOICE, using IN-Site data and visits.
SYSTEMS DEVELOPMENT

Key informants felt that the main impact of the first year of the NFCSP was to put the focus on the caregiver in care planning and to shift thinking. The NFCSP also has brought other players to the table—for example, the Alzheimer’s Association—both locally and at the state level. The new program has encouraged the use of new technology, including a pilot program for Alzheimer’s disease patients. This pilot is experimenting with the use of fall mats by beds, video cameras and door monitors. The five families served through the pilot have reported positive results.

In terms of coordination of caregiver support services at the state and local levels, informants had varying views. All state agency staff interviewed believed that state-level coordination existed, citing the setting of waiver policy at the state level, the approval of plans of care for Medicaid waiver services and the NFCSP coordination by BAIHS, in collaboration with I4A and the AAAs. On the other hand, stakeholders felt there was no state-level coordination and saw the state as having delegated coordination completely to the AAAs. As to local coordination, most saw AAA staff as fulfilling this function. Several mentioned that the AAAs all have a staff person in place who focuses specifically on caregivers. One stakeholder asserted that caregiver support services “aren’t really coordinated locally,” however. “There may be an informal network,” one respondent said, “but most referrals for caregiver services, in the respondent’s experience, come from physicians, friends and general word of mouth, rather than through AAA staff.”

Indiana does not have a body whose mission is to coordinate family caregiver support services across state departments. One respondent noted that the Long-Term Care Advisory Group, within the Office of Medicaid Policy and Planning, might be fulfilling this function to some degree. One stakeholder offered that FSSA might say it had such a coordination vehicle, “but it is disjointed.” State respondents differed as to whether they thought Indiana’s support program for family caregivers is integrated into the state’s other long-term care programs or stands alone. “What there is of it is integrated,” observed one informant.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN OLMSTEAD DECISION PLANNING

Indiana has had an Olmstead task force and has engaged persons with disabilities and their families and advocates in the state’s Olmstead plan development. Governor Frank O’Bannon (D), through executive order on September 18, 2000, instructed FSSA to:

- Conduct a comprehensive study of all services and programs available to people with disabilities in Indiana
- Evaluate current systems of service delivery
- Identify the array of services available and assess the demand and desire for these services in a less restrictive setting
- Identify barriers to achieving total integration into the community where the demand exists

The secretary of FSSA appointed an internal action team, composed of top administrators of programs for persons with disabilities and three subcommittees made up of consumers, families, providers and advocates. The subcommittees were focused on mental health, developmental disabilities and
aging/physical disabilities. Family members of consumers had the opportunity to express their concerns at three public meetings throughout the state in November 2000 and at 12 public meetings during which the draft plan was presented. The FSSA, as required, developed a report summarizing its Olmstead planning activities and resulting recommendations. Entitled *Olmstead-Comprehensive Plan for Community Integration and Support of Persons with Disabilities*, this report identifies six major policy directions and related options. The first two of the identified policy directions have direct impact on family caregivers.

1. **Increase Consumer Choice:** Enable individuals to receive the types of services they desire in the location they prefer. *Options:* Reduce reliance on institutional care by de-emphasizing nursing home care and reducing the state facilities’ census; use savings from decreased use of institutions to expand community-based care; use waiver mechanisms to make a full range of community supports available; cultivate new and creative community-based options.

2. **Support the informal network of family, friends, neighbors and communities.** *Options:* Develop methods for families and advocates to participate in quality assurance systems; strengthen education, training and respite services for family caregivers.

**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?” As shown here, Indiana stakeholders agreed that the priority was “low,” whereas BAIHS officials gave “high” priority to caregiver support in the state. One stakeholder did not respond.

<table>
<thead>
<tr>
<th>Number of Key Informants</th>
<th>Priority on Caregiver Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No response</td>
</tr>
<tr>
<td>3</td>
<td>→ Low</td>
</tr>
<tr>
<td>1</td>
<td>→ High</td>
</tr>
</tbody>
</table>

*Benefits and challenges:* Key informants cited several aspects of the caregiver support program that are most beneficial to family caregivers:

- Respite
- Training, especially to recognize when they need help
- Support programs
- Tips from peers
The challenges reported were the following:

- Need for a clear idea of the purpose of the program so that state and local staff and providers can be trained
- Funds needed to expand in a tight fiscal situation
- Limited use in Indiana of vouchers for anything
- Attitudes of the older population, who advocate for children’s issues but not for themselves
- Baby boomers’ lack of education on the issues and on the need to push for services

Major lessons learned:

- Caregivers do not have one specific need—they are a diverse group, and no one easy solution exists
- Because of the complexity of providing caregiver support, the program is changing as it is implemented
- The importance of flexibility must be emphasized
- It is important to be open to learning more about who caregivers are and to discovering new populations of caregivers, such as male employed caregivers

Opportunity for expanding caregiver support: Respondents noted several legislative or regulatory changes that might enhance Indiana’s family caregiver support programs. One suggested that Indiana needed to have specific legislation recognizing family caregivers and their need for support. Another underscored the importance of solving the fiscal intermediary issue, thereby bringing consumer choice into the Medicaid waiver programs. The need to add questions about the family caregiver to the E-Screen was also noted.

Despite the current fiscal situation, most respondents expected to see expansion over the next three to five years in Indiana’s state-funded programs to support family caregivers. The prospects for expanding programs that are exclusively state funded were not good, but some expansion was seen as possible by using Medicaid waiver services to complement CHOICE services. Moving Medicaid-eligible CHOICE recipients to the Aged and Disabled waiver was seen as key to maximizing federal dollars and enabling CHOICE to reach more people.

Recommendations for other states: State respondents offered several recommendations, based on their experience to date:

- Work closely with the AAAs to develop and deliver the program.
- Design the system to fit the change you are trying to make, rather than try to fit it into your current system. Don’t feel that you have to squeeze your caregiver program into the current box. You can get a new box if you need to.
- Keep caregivers in the center of the program. Listening is key, and bureaucrats often are not good listeners.
NOTES

1 U.S. Census Bureau, Urban and Rural Population: 1900 to 1990 (October 1995).
6 MapStats-Indiana.
8 Ibid.
9 Ibid.
13 Indiana Family and Social Services Administration, Community and Home Options to Institutional Care for the Elderly and Persons with Disabilities (CHOICE) Guidelines and Procedures (Indianapolis: Division of Disability, Aging and Rehabilitative Services, rev. June 1, 2001), 2.
16 Indiana Family and Social Services Administration, Real Choice Systems Change Grant Narrative, www.in.gov/fsa/servicedisabl/olmstead/realnar.html (June 2002).
20 Indiana Family and Social Services Administration, Community and Home Options to Institutional Care, 16.