Family Caregiver Support:

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

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PENNSYLVANIA

Overview

Pennsylvania is a moderately sized, densely populated mid-Atlantic state with less racial and ethnic diversity than the country as a whole. The Commonwealth of Pennsylvania is relatively unique in that it has the largest rural population of any state, yet it is the sixth most populous state in the nation.[1] In addition, Pennsylvania has the third-highest percentage of older persons in the country. The state's long-term care system has emphasized the provision of home and community-based services and has recently focused on expanding access to these services. State-only–funded programs for the elderly and for persons with disabilities have existed since 1987 and have received significant funding increases in recent years.

Pennsylvania's state-funded program to provide caregiver support began in 1987 with a demonstration program that went statewide in 1991. It was one of the models on which the National Family Caregiver Support Program (NFCSP) was based. When the program was first developed, it was a separate initiative, but it evolved over time into a more integrated system of caregiver support. While the infusion of federal funds has allowed the state to serve more caregivers, it has also allowed them to serve a broader range of needs that complement existing core services. The state's caregiver support services are characterized by:

- Centralized policymaking and administration with statewide policies and standards to ensure a consistent approach to caregiver support
- Fully integrated programs and services that are seamless to consumers (i.e., family caregivers and care recipients)
- Flexibility to meet the individual needs of family caregivers at the local level

Pennsylvania respondents noted that the major service needs of family caregivers are (1) respite care, (2) supplemental services (e.g., consumable supplies, home modification) and (3) personal care (e.g., hands-on help with activities of daily living, or ADLS).

Introduction

Pennsylvania is an "old" state, meaning that it had a long-time state general fund program providing caregiver support before the passage of NFCSP. The project team conducted a site visit between May 2 and 3, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies interviewed include:

Pennsylvania Department of Aging, Division of Quality Management and Long-Term Care

- Caregiver Support Program (NFCSP funded and state funded)
- OPTIONS (State lottery funds)
- Bridge (Tobacco settlement funds)
- Aged Medicaid waiver

Pennsylvania Department of Public Welfare, Bureau of Long-Term Care
- Aged Medicaid waiver

Stakeholders interviewed were from:
- Pennsylvania Association of Area Agencies on Aging
- Alzheimer's Association, Greater Pennsylvania Chapter

Five programs are featured, all of which are administered by the Pennsylvania Department of Aging:
1. Pennsylvania Family Caregiver Support Program
2. National Family Caregiver Support Program
3. Bridge program
4. OPTIONS program
5. Aged Medicaid waiver

Background

Pennsylvania is a moderately sized, densely populated mid-Atlantic state with a population of 12.3 million residing in 67 counties.[2]

The state has a mix of major metropolitan and rural areas, with fewer minorities and low-income populations than the nation as a whole. Pennsylvania has 14.6% its of residents living in nonmetropolitan areas, compared to 21.8% in the nation as a whole, although it has in absolute terms the largest rural population.[3] In 2000, personal income per capita was $29,504, nearly the same as the national average of $29,676.[4] About 10.9% of Pennsylvania's population live below the federal poverty level (vs. 13.3% U.S.).[5] Pennsylvania ranks 29th nationally in percentage of households with Internet access.[6] Although the state's African-American population does not vary significantly compared to that of the U.S. (10.0% vs. to 12.3% U.S.), Pennsylvania has less racial and ethnic diversity than the nation as a whole (85.4% Caucasian compared to 75.1% U.S.)[7] (table 1).

An estimated 2,430,821 persons in Pennsylvania, or 19.8% of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). Pennsylvania ranks third nationally in the number of older persons (ages 60+) residing in the state.[8] The state's lower racial and ethnic diversity is also present in the 60+ population. African Americans ages 60+ are 6.7% of the population (vs. 8.4% U.S.). For Hispanics, however, the percentage drops to 0.9% (vs. 5.4% U.S.).[9]

Pennsylvania ranks seventh nationally in the proportion of its population ages 85 and older. In 2000, 237,567 persons, or 1.9% of Pennsylvania's population, were ages 85+.[10] While Pennsylvania already ranks high in the percentage of older persons, that percentage is likely to increase because of the state's faster-than-average growth in the aging population. This trend may be explained by the state's relatively slow population growth as compared to that of the nation as a whole (0.1% vs. 5.2% U.S.).[11]

An estimated 1,202,411 family caregivers reside in Pennsylvania. These family caregivers provide about 1,119 million hours of caregiving per year at an estimated value in 1997 of $9.16 billion.[12]

Pennsylvania has a relatively well funded system of home and community-based services, using a variety of resources to pay for program implementation and expansion. Of note are the significant funding increases—more than $100 million each year from FY 1996 to FY 2001—that Medicaid waiver programs have received.[13] The legislature appropriated $45 million in tobacco settlement funds to expand the number of Medicaid waiver slots and fund other home and community-based services.[14] Additionally, Pennsylvania is the only state in the nation to have earmarked all proceeds from its state lottery exclusively for services assisting older persons.

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

	Pennsylvania	United States
Total Population Characteristics		
Total Pop.[b]	12,281,054	281,421,906
% African American[c]	10.0%	12.3%
% Hispanic [d]	3.2%	12.5%
Older Population Characteristics		
Pop. 60+[e]	2,430,821	45,797,200
% 60+[f]	19.8%	16.3%
National ranking 60+ [g]	3	NA
Pop. 65+[h]	1,919,165	34,991,753
% 65+[i]	15.6%	12.4%
National ranking 65+ [j]	2	NA
Pop. 85+[k]	237,567	4,239,587
% 85+[l]	1.9%	1.5%
National ranking 85+[m]	7	NA
% increase 1990–2000 60+ pop.[n]	-0.2%	9.4%
% White (60+)[o]	91.2%	82.4%
% African American (60+)	6.7%	8.4%
% Hispanic (60+)	0.9%	5.4%
% Asian (60+)	0.7%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics [p]		
# of caregivers (1997)	1,202,411	25,798,370
Caregiving hours (millions) (1997)	1,119.2	24,013.1
Value of caregiving (millions) (1997)	$9,155.1	$196,426.7
Economic Characteristics		
Per capita income [q]	$29,539	$29,676
% of pop. below poverty (1997)[r]	10.9%	13.3%
Internet		
% of households w/Internet access (2001)[s]	40.1%	41.5%
Nat'l ranking of households w/Internet access	29	NA

a Unless otherwise noted, all data are from 2000.
b Mapstats-Pennsylvania, *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-Pennsylvania.
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 agencies: the Pennsylvania Department on Aging (PDA) and the Pennsylvania Department of Public Welfare (PDPW). Programs administered by PDA make use of several sources of funding, including federal matching funds, state general revenue, state lottery and tobacco settlement dollars. The Pennsylvania Family Caregiver Support Program is the only PDA program funded through state general funds; however, a significant portion of PDA's budget is financed through the state lottery.[15] Pennsylvania has also committed 13% of its tobacco settlement to fund home and community-based services.

The PDA is a freestanding department, serving as the State Unit on Aging and administering the provisions of the federal Older Americans Act, including the new NFCSP, as well as the state-funded Family Caregiver Support Program (FCSP). The governor appoints the secretary, who has cabinet-level status.

The infrastructure of Pennsylvania's aging network is a statewide system of 52 Area Agencies on Aging (AAAs) that serve Pennsylvania's 67 counties. The state's AAAs provide assessment and case management for all PDA programs, including the Aged Medicaid waiver, NFCSP, state-funded FCSP, OPTIONS, Bridge and other Older Americans Act programs. AAAs may also provide directly or by subcontract services such as transportation, legal assistance, home support, home-delivered meals and long-term care ombudsmen. AAAs are either units of county government or private, nonprofit corporations.[16]

The PDPW is responsible for oversight of Medicaid programs and services as the single state agency for Medicaid. Of Pennsylvania's 11 home and community-based Medicaid waivers, the PDPW administers 10.[a] The PDPW contracts with the PDA to administer the Aged Medicaid waiver,[b] which provides services to about 7,300 aged beneficiaries in the state (7,400 total slots). In addition to receiving federal funds, the state has funded an expansion of 1,000 waiver slots with tobacco settlement monies.

In 2002, the PDPW was awarded a $1.4 million Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The goal of the grant is to expand or improve community-integrated services for the disabled or for those with a long-term illness.

Overview of State System of Caregiver Support[c]

Pennsylvania has both an integrated and a well-developed system of home and community-based services. Other PDA-administered programs that provide some services to support family and informal caregivers include OPTIONS, Bridge and the Aged Medicaid waiver.

Pennsylvania's FCSP was developed in 1987 as a result of inclusion in the campaign platform of former Governor Bob Casey (D).[d] The demonstration was expanded to nine additional sites in 1989 and went statewide in 1991. The support for this program and other aging services continued through the term of Tom Ridge (R), who left office in 2001, and the term of current Governor Mark Schweiker (R). Key informants indicated that the FCSP "is, hands down, the most popular program we've ever had."

Pennsylvania has fully integrated the FCSP, initially conceived as a stand-alone program, into its other long-term care programs. Noted one key informant, "Family caregiver programs are integral parts of the long-term care system, and they shouldn't be held separate from the rest of the long-term care system."

When the NFCSP was implemented, Pennsylvania used the program to supplement and expand access to services under its state-funded programs. According to key informants, the state and federally funded programs are administered to "appear as if they are one program out in the field." That is, consumers are "blind" as to the funding source of the services they are receiving. This historical focus on integrated, flexible programs within the state's home and community-based services was a common theme cited by many respondents.

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a Pennsylvania has 11 home and community-based service waivers, including Infants, Toddlers, and Families Waiver; Consolidated Waiver for Individuals with Mental Retardation; Person/Family Directed Support Waiver; Attendant Care Waiver; Independence Waiver; OBRA Waiver; AIDS Waiver; Michael Dallas Waiver; Elwyn Waiver; Aging Waiver; and Long-Term Care Capitated Assistance Program.

b In Pennsylvania, the Aged Medicaid waiver is referred to as the Pennsylvania Department of Aging (PDA) waiver.

c The overview of the State system of caregiver support includes information on Program Background and Development. Additional background information on Pennsylvania's programs serving family and informal caregivers can be found in Family Caregiver Alliance's October 1999 study *Survey of Fifteen States' Caregiver Support Programs: Final Report.*

d See the Family Caregiver Alliance 1999 study *Survey of Fifteen States' Caregiver Support Programs: Final Report* for further details on development of caregiver support in Pennsylvania.

Pennsylvania also provides some caregiver support services, such as respite care, through its OPTIONS and Bridge programs. OPTIONS, created in 1989, provides a wide range of both facility-based and home and community-based services, mostly to older, frail Pennsylvanians. There is no income eligibility requirement for OPTIONS; however, there is a sliding-scale cost-share requirement. The Bridge program, which began providing services in January 2002, provides home and community-based services to those who need a nursing home level of care but do not meet the asset test associated with the state's Aged Medicaid waiver. Consumers are required to make a 50% cost-share, with the expectation that they will draw down their assets and eventually qualify for waiver services.

Pennsylvania's Aged Medicaid waiver began in 1995 as a way to slow the growth in nursing homes and includes respite care as one of its benefits. Respondents indicated that other benefits, such as home support, environmental modifications and personal care, also help family and informal caregivers, although this may not be explicitly stated.

When asked if family and informal caregivers are recognized as a central component of a comprehensive long-term care system, key informants agreed that they are, citing the wide variety of programs providing services to family caregivers as evidence of this. Further, family and informal caregivers are explicitly recognized in Pennsylvania statute, the legislation that created the state's caregiver support program, and in a set of regulations that are a part of Pennsylvania code.[e] The PDA also employs a staff person whose responsibilities include coordinating the NFCSP and the state-funded FCSP.

Most rewarding: Key informants cited the reward of seeing families benefit from services but also noted that flexibility built into the new federal program was very positive. According to one key informant, the U.S. Administration on Aging (AoA) was "so respectful of our program in the design of the federal program…it's effectively allowed us to do the kind of things that we wanted to localize the program without having to reopen the state legislation, which is a major act within itself…[We] used the federal program to empower us to do things that we couldn't do before." Respondents also noted the ability to allow people to live out more of their lives at home and the cost-savings associated with supporting home and community-based care, as opposed to nursing home care, as rewarding program aspects.

Biggest challenge: Key informants indicated three challenges: (1) the difficulty in implementing and processing a system of cash payments when the FCSP program began, (2) Medicaid estate recovery provision and (3) the difficulty in keeping the number of Medicaid waiver slots ahead of demand. Regarding cash payments, state officials noted that AAA staff encountered some complications when implementing the system. They ascribed the difficulty to the shift in the way AAAs had traditionally provided services and also to the responsibility to provide the necessary education to consumers about how to invoice for services.

e The Pennsylvania code referencing the state-funded caregiver support program can be found in Pennsylvania Code Title 6, Chapter 20.

Funding

For FY 2001–02, Pennsylvania expended $9.3 million on the state-funded FCSP. In FY 2002, the state received $6.9 million for the NFCSP with the PDA contributing $2.1 million for the required state match. Combined, the FCSP and NFCSP provide less than 3% of the PDA's overall budget. The PDA does not provide specific funding levels for their other home and community-based programs, such as OPTIONS and Bridge. The PDA block grants funds for these services and then requires that the AAAs spend a certain amount of the funds for in-home services. For FY 2001–02, the PDA block grant to the AAAs is $288 million. Of this, AAAs were required to spend at least $158 million, or about 22% of PDA's total budget, providing in-home services.

Exhibit 1. FY 2000–01 PDA Block Grant Expenditures by Service [a]

	Expenditure	Consumers Served
Adult Day Care	$11.51 million	3,747
Attendent Care	$3.02 million	174
Consumer Reimbursement	$8.70 million	5,554
Environmental Modifications	$1.83 million	1,697
Home Support	$4.87 million	10,313
Overnight Supervision	$242,677	208
Personal Assistance Services	$5.86 million	1,722
Personal Care Services	$42.24 million	22,417

For FY 2000–01, total expenditures for the Aged Medicaid waiver were $63.7 million, serving a total of 7,464 consumers. PDA does not specifically break down expenditures for respite care. Instead, it accounts for services in categories that include attendent care, adult day health and overnight supervision. (No data were available for FY 2001-02 expenditures.)

Exhibit 2. FY 2001–02 Aged Medicaid Waiver Expenditures by Service

	Expenditure	Consumers Served
Adult Day Care	$3.47 million	1,127
Attendent Care	$5.91 million	1,372
Environmental Modifications	$266,024	192
Home Support	$2.54 million	1,090
Overnight Supervision	$2.44 million	809
Personal Assistance Services	$361,000	2,280
Personal Care Services	$26.89 million	4,366

a Services funded through the block grant may also receive funding from other sources, such as cost-sharing.

Pennsylvania has made use of a variety of funding sources for its home and community-based services. In FY 2001, the state received about $398 million in tobacco settlement funds. Of these funds, the legislature appropriated almost $45 million (13% of annual tobacco settlement revenue) in new, annual funding for home and community-based services.[17] In FY 2002, Pennsylvania received nearly $478 million in tobacco funds, again earmarking 13% for home and community-based services. Pennsylvania is also the only state in the nation that exclusively targets state lottery fund proceeds to pay for services supporting older persons. OPTIONS is exclusively funded by the Pennsylvania state lottery, whereas the Bridge program is funded by tobacco settlement monies.

Key informants described the current budget situation in Pennsylvania as "not bad." Challenges due to the economy include a leaner budget (no cost-of-living adjustment included for the current budget year) and difficulty growing programs, particularly in expanding home and community-based services. Key informants cited utilization of tobacco funds for long-term care as one reason that short-term financial problems were not as dire in Pennsylvania as in other states. Another reason is that savings in Medicaid due to reduced nursing facility utilization have been significant.

Program Administration

In Pennsylvania's current system of support, the 52 AAAs coordinate caregiver services at the local level. At the state level, services are coordinated through regulations, directives, training and periodic inquiries to AAAs regarding resource reallocation. State officials identified two major roles that the PDA plays with regard to caregiver support services. The first is to administer the state and federal caregiver programs, in addition to administering the Aged Medicaid waiver. The second is to "feed" families into the waiver where appropriate. Policy development and program administration are centralized at the state level, with a strong focus on integrated assessment, service delivery and single point of entry at the AAA level. According to key informants, the agency has worked "to redirect the program…to make it more like a part of the long-term care system rather than a freestanding program." PDA officials described their relationship with the AAAs as a democratic one and indicated that they work "hand-in-glove" with the Pennsylvania Association of AAAs (P4A). State officials indicated that they intentionally keep policies and standards broad to allow AAAs to meet local and individual needs. They noted, however, that some AAAs occasionally narrow the parameters set by the PDA. Whereas the PDA encourages any service that will prolong or enhance the caregiver relationship (i.e., purchasing a washer and dryer for an arthritic caregiver who was hand washing clothes; allowing a caregiver to bank respite benefits and go on vacation), some AAAs have preferred "stricter" program guidelines. One key informant ascribed the narrowing of parameters to accounting challenges or simple disagreements over the "politics" of providing so much flexibility for consumers.

The OPTIONS and Bridge programs are administered by the PDA and the AAAs. Home health agencies and other service providers have contracts with the AAAs to provide services.

With regard to the Aged Medicaid waiver, the PDA is responsible for administering the program. Officials of the PDA indicated that they try to get "buy-in" from the various stakeholders and usually assist PDPW and the AAAs in achieving consensus in the process of developing guidelines and policies. Respondents from the PDA stated that they see themselves in the role of policy brokers, rather than as policymakers.

The PDA has focused resources on publicizing caregiver support services by creating two websites—a comprehensive long-term care site as well as the PDA site. Additional publicity includes speaking engagements throughout the state to increase awareness of caregiver needs and the NFCSP. With regard to the Aged Medicaid waiver, state officials have focused on marketing home and community-based services as a product line, rather than as a set of stand-alone services.

Program Eligibility/Assessment Process

Pennsylvania's caregiver support and home and community-based programs are based on an integrated care management model at the AAA level. In this effort, the PDA uses programs to complement each other, and a consumer who does not meet eligibility for one program often may use similar services from another program with different eligibility criteria.

Regarding assessment, Pennsylvania incorporates caregiver information as part of its comprehensive assessment instrument used for all of the home and community-based care programs administered by PDA.[18] The assessment includes measures of caregiver burden and stress, as well as of the ability and capability of the caregiver to assist the care recipient.

Each AAA administers the uniform assessment instrument directly, although state officials cited the possibility that a small number of AAAs may contract out this service. Assessments are conducted in person, usually in the home. Reassessment is generally done every six months, although the standard is "as needed." The PDA is currently in the process of revising its assessment instrument.

The care plan is based on the assessor's determination of need. Once needs have been established, the assessor determines which of the PDA's home and community-based service programs is most appropriate for the situation. The intent of the care plan and the resulting services is to enhance, preserve and prolong the caregiving relationship. Key informants noted that there was at one time in the state-funded FCSP a movement to exclude assessing the care recipient at all and to focus only on the caregiver. This changed, however, as the program moved from a stand-alone set of services to a more integrated part of the state's long-term care system as a whole.

Eligibility for PDA programs are as follows:

State-funded FCSP: Family or informal caregivers of any age who provide care to persons 60 years or older or to persons of any age with a diagnosis of dementia. The care recipient must have one ADL deficit. Although the NFCSP requires that the care recipient be unable to complete two ADLs rather than only one ADL, as in the state program, a PDA respondent noted that "It is a distinction without a difference…My experience is that ADLs come in pairs, usually." The respondent also pointed out that, in addition to the ADL deficits of the care recipients, many of the caregivers served have some instrumental activities of daily living (IADL) deficits.

There are no income requirements for "soft," or core, services (i.e., support groups, caregiver education and training, etc.). Income requirements do exist for "hard" services (i.e., respite and consumable supplies). If income exceeds 380% of poverty level, no reimbursement for hard services is provided. For incomes between 380 and 200% of poverty level, Pennsylvania uses a sliding scale. Consumers below 200% of poverty level are entitled to reimbursement for the full amount of services, within a $200 cap.

The assessment is uniform, and both the family caregiver and the care recipient are considered the client in the program.

NFCSP: Family or informal caregivers of any age who provide care to persons 60 years or older, as well as caregivers ages 60 and over who care for children ages 18 or younger.[f] The care recipient must have at least two ADL deficits. There are no income requirements for "soft," or core, services. The same sliding scale used for the FCSP is used for the NFCSP.

OPTIONS: Care recipients ages 60 or older who have "some frailty" in their physical or mental health status.[19] There are no financial eligibility requirements for OPTIONS; however the program has a sliding-scale cost-sharing component. The assessment is uniform across the state, and the care recipient is the identified client in the program.

Bridge: Care recipients ages 60 or older who require a nursing facility level of care. Net incomes must be less than $1,635 per month, with assets of at least $2,000 but not more than $40,000.

The assessment is uniform across the state, and the care recipient is the identified client in the program.

Aged Medicaid waiver: Care recipients ages 60 or older, disabled (according to the AAA functional review) or meeting the medical criteria for Medicaid nursing home level of care. The care recipient cannot exceed $2,000 in resources, and income is limited to 300% of the Federal Benefit Rate ($1,593 per month as of August 2001).

Consistent with Medicaid policy in general, respondents noted that the care recipient is the identified client, and 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. The assessment instrument maximizes informal supports to the extent possible before including other services in a care plan. Respondents acknowledged that utilizing informal care is an important part of staying within the Medicaid waiver cost cap (80% of nursing home costs). Further, they noted that a family caregiver's needs and ability to provide care are formally assessed, as are the needs of the care recipient, although they acknowledged that the assessment tool is focused more on the care recipient.

The PDA recently implemented a system of cost-sharing. Before the system was implemented, cost-sharing had always been included in the FCSP but not required in other community-based long-term care programs, such as OPTIONS. AAAs did have the flexibility to apply cost-sharing to their programs, and 26 of the AAAs had some level of cost-sharing. As of January 1, 2002, the PDA required that all AAAs cost-share—using the same standard—for consumers whose income is above 125% of the federal poverty level, currently $923 for one person or $1,244 for a couple. PDA staff noted that two-thirds of the people they serve are under 125% of the poverty level.

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

Services

Rather than focus on one specific service category within the FCSP or NFCSP, the state emphasizes the flexibility that each AAA has to meet individual consumer needs. Consumers determine what they need and are then reimbursed for everything from respite care to consumable supplies. Reimbursement is typically limited to $200 per month, but AAAs can reimburse for costs as high as $500 as long as their caseload average does not exceed $300. Describing the program, one state official said that "there is no menu [of services]. It's what the consumer wants. The program can literally be reinvented every time it goes into a new family…That's the beauty and the secret of our program." The program does strictly prohibit reimbursement for prescription drugs because of the recent enactment of a state-subsidized prescription drug program.

Some of Pennsylvania's AAAs provide direct services, whereas others contract out these services. Typically the services AAAs provide include information and assistance, assessment and case management. PDA staff indicate that "soft," or core, services—such as counseling and support groups—are not as highly utilized as "hard" services, such as reimbursement for respite care. In addition to the $200 monthly cap, reimbursements are available for home modifications and assistive technology, with a lifetime maximum of $2,000. Key informants stated that "We don't want to be a housing program, but we do want to incorporate technology where it's appropriate, and…[we] do so a little more liberally than the federal [NFCSP] program."

Respondents indicated that if a particular AAA overspends its caregiver support program funds, then that AAA will put clients on a waiting list. State officials said this is relatively rare, however. Further, if a consumer needs additional services above the cap, other programs may provide some assistance. In fact, key informants said that they have "many arrows in their quiver" that allow them to replicate family caregiver support services in other programs.

For respite care, caregivers can purchase services in any setting they choose and can hire friends (but not family members) as providers. Caregivers also have the option of banking respite benefits in order to take a vacation or for other reasons.

With regard to the Aged Medicaid waiver, many of the same services are available as in other PDA programs. Key informants indicated that caregiver education and training could be provided under the "care management" component. The only service cap that exists relates to the overall requirement that Medicaid waiver services must be no more than 80% of nursing home costs; it is not a cap on a specific service, such as respite care. Covered respite services include in-home respite assistance, adult day health services, overnight respite in a facility and access to respite weekends. Key informants described the program as having more statewide standards than under the state and federal family caregiver support programs administered in Pennsylvania. Waiting lists do not exist for Medicaid waiver services.

Services provided within PDA programs include the following:

NFCSP: $200 monthly reimbursement for caregiver-identified services and supplies; $2,000 reimbursement (lifetime maximum) for home modification or assistive technology; caregiver education and training; support groups and other "soft" services.

State-funded FCSP: $200 monthly reimbursement for caregiver-identified services and supplies; $2,000 reimbursement (lifetime maximum) for home modification or assistive technology; caregiver education and training; support groups and other "soft" services.

OPTIONS: Respite care; home modifications; home support activities.

Bridge: Respite care; home modifications; home support activities.

Aged Medicaid waiver: Respite care; home modifications; home support activities.

Major services needed by caregivers: At PDA, respite was identified as the major service category needed by family caregivers. Medicaid officials indicated that personal care, such as hands-on help with ADLs, was the major service needed.

Table 2. Family Caregiver Support Services in Pennsylvania

Program	Pennsylvania FCSP and NFCSP	OPTIONS	BRIDGE Program	Aged/Disabled Medicaid Waiver
State Administrative Responsibility	Pennsylvania Department of Aging	Pennsylvania Department of Aging	Pennsylvania Department of Aging	Pennsylvania Department of Aging
Local Service Delivery	AAAs [a]—information, education, assistance, assessment & case management	AAAs —information, education, assistance, assessment & case management	AAAs —information, education, assistance, assessment & case management	AAAs — assessment & case management only
Funding Source	State general funds,[b] Older Americans Act, Title III-E	State lottery funds	Tobacco settlement funds	Medicaid 1915 (c) waiver
Expenditures FY 2001-02	FCSP—$9.3 million NFCSP—$6.9 million	NA[c]	NA[d]	$63.7 million [e]
Client Population	Family caregiver, care recipient	Care recipient	Care recipient	Care recipient
Eligibility Criteria				
Age	Family caregivers of any age of persons 60+[f] Family caregivers of care recipient of any age with dementia diagnosis (FCSP only)	60+ care recipient	60+ care recipient	60+ care recipient
Income	None	No income eligibility	$1,635 or less in income; assets between $2,000 and $40,000	$2,000 (assets) 300% of federal poverty rate [g]
Functional Ability	1 ADL need (FCSP) 2 ADLs needs (NFCSP)	Nursing home level of care	ADL or IADL deficiency	Disabled [h] or nursing home level of care
Uniform, Statewide Caregiver Assessment	Yes	Yes	Yes	Yes

a AAAs = Area Agencies on Aging.
b These funds are for Pennsylvania's state family caregiver support program.
c Pennsylvania does not budget specifically for this program but rather block grants the funds to the AAAs, which allocate among various programs providing home and community-based services.
d Ibid.
e FY 2000-01.
f Eligibility for the NFCSP also includes caregivers ages 60 and older who are caring for children 18 or younger, including those affected by mental retardation or with developmental disabilities.
g Federal poverty level was $1,593/month as of August 2001.
h Disability must be assessed according to AAA functional review.

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

Program	Pennsylvania FCSP and NFCSP	OPTIONS	BRIDGE Program	Aged/Disabled Medicaid Waiver
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite care Home modifications Home support activities	Respite care Home modifications Home support activities	Respite care Home modifications Home support activities
Respite Cap	$200 per month [i]	No	No	No specific cap— total expenditures per recipient must be less than 80% of nursing home cost
Consumer Direction	Yes	Yes	Yes	Yes
Family Caregivers Paid as Respite Providers	No	Yes (not spouses)	Yes (not spouses)	Yes (not spouses)

i PDA uses $200 as a guideline for capping services, although this is not an absolute cap. AAAs may reimburse for as much as $500 per month, as long as the caseload average does not exceed $300.

Consumer Direction

Both the national and state-funded caregiver support programs and the Aged Medicaid waiver allow for consumer direction. For the NFCSP and FCSP, the PDA emphasized the importance of informal caregivers as providers, rather than more formal, agency-provided services. State officials indicated that this works better, both because it is less expensive and because the relationship between the caregiver and the provider is "much more comfortable." In addition to hiring their own respite providers, consumers can receive reimbursement for almost any service (with the direct exclusion of prescription drug reimbursement). Friends and neighbors can be paid to provide personal care; however, all relatives are specifically prohibited from being reimbursed for this service. The basis for the regulation, the PDA respondents indicated, is the assumption that "family members, whether primary or otherwise, are going to give the services…and we're supporting that noble initiative."

In both the OPTIONS and Bridge programs, family (except for spouses) and friends can be hired to provide both respite and personal care services.

Medicaid officials characterized consumer direction in the Aged Medicaid waiver as "informal." Family members, excluding spouses, can be paid to provide personal care and respite care. Respondents cited empowering consumers and dealing with a workforce shortage as reasons for allowing the reimbursement of family members to provide personal care. Respondents further indicated that background checks for family caregivers providing personal care have been a big debate in Pennsylvania, although currently they are not required.

Quality Assurance and Evaluation

Officials from the PDA stated that they currently do not collect any data on family caregivers and indicated that they will soon collect a "rudimentary" level of data. Data is not aggregated or mined at the state level. The PDA does, however, plan to automate its client-tracking system in the near future. The goal is to begin collecting, in an automated format, at least the information contained in the current assessment tool. Key informants indicated that there have been glitches in developing this automated system, including the challenge of designing a system that meets the needs of 52 AAAs, each with a distinct organizational structure and with varying data systems and equipment. While respondents identified the inability to do statewide analysis as a shortcoming, they felt that the system was functional in terms of assisting consumers. One state official indicated that "the system operationally knows the information about caregivers. We know it at the level where we can actually help the consumer, but knowing it at the level where you're going to do statewide analysis is what we don't have."

Under the Aged Medicaid waiver, respondents stated, Pennsylvania's family caregiver support programs collect more data on their consumers than PDPW does on waiver participants. Service utilization and spending by recipient were the example offered of data collected. Respondents also indicated that the current system, the Medical Assessment Management Information Systems, is being revised and should be more user friendly to operate and provide more flexibility with regard to data collection.

Systems Development

Respondents noted that their family caregiver support programs have been very popular, that "they are everybody's favorite program." The program appears to be popular not just with caregivers and care recipients, but with AAA staff as well. State officials cited higher "payoffs" among caregiver support program consumers and believed this was in part due to the intense relationship that staff forms with them.

In terms of the impact of the federal program on the existing state program, a PDA official said,

> "The NFCSP was basically used to expand what we were already doing and allow us to do things that we wanted to do that state law didn't let us do. And it's been a very positive experience as far as I know, down to the AAA level. [It's] not a real hard program to implement once you learn how to pay consumers…It's taken a really neat program and made it an almost perfect program."

The official went on to say that the FCSP has

> "incorporated an awareness of the caregiver and their needs into the overall long-term care structure. So even though it's...probably 5% of our community-based long-term care budget, that caregiver section is in every assessment that's done except for people who only want to go to a nursing home, who don't even want to consider community-based care. If somebody's even considering community-based care, the caregiver is now assessed, and their needs are assessed. So I think our whole system is more caregiver-friendly than it would have been had we not had the Family Caregiver Support Program."

Pennsylvania does not have a body whose mission is coordination of family caregiver support services across state departments. Pennsylvania does have a long-term care project with a general focus on home and community-based care, rather than specifically on caregiver support. All respondents stated that Pennsylvania's caregiver support program is integrated into the state's other home and community-based services, as opposed to a stand-alone program.

State Involvement of Family Caregivers in *Olmstead* Decision Planning

In August 2000, the Home and Community-Based Care Project was launched to address issues related to *Olmstead* planning. Components of this project include the following teams: resource facilitation, assessment, tracking and data management, policy, program and operations, communications and quality management.[20] While consumers have been involved in the task force associated with the project, key informants did not believe that family caregivers were necessarily represented.

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?" State officials agreed that the priority statewide was "medium," but indicated that in specific programs the priority was much higher. Stakeholders' perceptions varied, with one stakeholder indicating a "low-medium" priority, the other "medium-high." A summary of all responses is provided here.

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

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

- ✧ Flexibility, all the way down to the consumer level
- ✧ The Aged Medicaid waiver, which is the best program available for care recipients who need a high level of care

The following challenges were reported:

- ✧ Inflexibility at the federal level (regarding Medicaid)
- ✧ The need to keep resources flowing

Major lesson learned: Pennsylvania's respondents cited flexibility as one of the keys to a successful program, recommending that state agencies work with AAAs in a way that doesn't allow them to take away any flexibility. Informants also recommended that family caregiver support programs integrate the intake, assessment and service delivery system with the overall community-based long-term care system in a manner that facilitates usage across programs.

Referring to the PDA and PDPW, other case study respondents reported that "if incentives are aligned, two agencies with vastly different views and priorities can partner successfully."

Opportunity for expanding caregiver support: All Pennsylvania respondents indicated optimism about expanding programs. The PDA is interested in expanding the grandparents-raising-grandchildren component of the caregiver support programs, in addition to components for older people taking care of adult children with mental retardation or developmental disabilities. The PDPW is interested in working internally to document the shift toward home and community-based care and the savings it generates to make the case for funding expansions.

Recommendations for other states: State respondents offered two recommendations based on their extensive experience:

- ✧ Ensure flexibility in the program.
- ✧ Integrate intake, assessment and service delivery within the overall long-term care system so that all services and funding needs are integrated.

Notes

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3 M. Birnbaum, *Health Policy for Low-Income People in Pennsylvania* (Washington, D.C.: The Urban Institute, 1998).
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5 Ibid.
6 Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, *www.governing.com/source.htm*. Source for Internet access is the National Telecommunications and Information Administration, 2001.
7 Ibid.
8 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group, www.aoa.gov/aoa/stats/2000pop/percentxstate.html* (April 1, 2000).
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13 National Conference of State Legislatures, *State Long-Term Care: Recent Developments and Policy Directions* (Washington, D.C.: National Conference of State Legislatures, 2002).
14 Ibid.
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18 L. Friss Feinberg, *Recognizing the Work of Family and Informal Caregivers: The Case for Caregiver Assessment,* prepared for the United Hospital Fund, New York, 2002.
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20 National Conference of State Legislatures, *The States Response to the Olmstead Decision: A Work in Progress* (Washington, D.C.: National Conference of State Legislatures, 2002).