

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Pennsylvania – Resource Counseling and Financial Assistance for Informal Caregivers

Issue: Family Caregiver Support Program

Summary

Pennsylvania's Family Caregiver Support Program is a flexible program designed to support the primary caregiver and family in ways specific to their needs and preferences. Pennsylvania uses state and recently available federal funds to allow the caregiver to choose the services most needed to help care for an older relative at home and provide financial assistance with out-of-pocket expenses. An early evaluation of the program found the services were effective in supporting informal family caregivers.

Introduction

A vast majority of help for older people with disabilities is from informal caregivers, usually spouses and adult children. Relieving caregiver burnout may allow people to remain in their own homes longer and prevent nursing home admissions. Nurturing caregiver relationships can also prevent dependence on government programs and improve the quality of life. Individuals with chronic illnesses and/or disabilities need a wide array of information and services, usually over an extensive period of time.

Most help for older people with disabilities is from informal caregivers

This report briefly describes the Commonwealth of Pennsylvania's Family Caregiver Support Program (FCSP), administered by the Department of Aging, that offers a comprehensive service package with specific funding and services for family caregivers. This document is based on written materials pertaining to Pennsylvania's Family Caregiver Support Program, a report published by the Family Caregiver Alliance, and interviews with state and local staff that manage the program.

Intervention

The major focus of the FCSP is to reinforce the care being given at home to family members in

poor health. The caregiver and person who need supports first receive an assessment to determine what benefits best meet their needs. Each caregiver and person work with a specially trained social worker to design a care plan which helps meet the family's needs. The social worker also provides information about federal and state entitlement programs, Medicare supplemental and long-term care insurance, caregiver support groups, and techniques for better caregiving. The assessment is the same assessment required for several other home and community-based services (HCBS) programs, including a Medicaid home and community-based services waiver for people age 60 and older. The social worker can help the person who needs supports enroll in one of these other programs if necessary.

The social worker also provides information about other programs, and caregiver support groups

Regardless of household income, caregivers and the person needing supports can use several services through AAAs. These services include care management, legal consultation, support groups, caregiver education and training, and counseling. Title III of the Older Americans Act funds many of these services, which are available nationwide from AAAs.

Limited financial assistance for the purchase of other services and items is available for households with income at or below 380% of the poverty line. These services include respite care and supplies and equipment not covered by Medicare and Medicaid. Assistance is available on a sliding scale depending on total household income. An unusual feature of Pennsylvania's program is that the caregiver and the person who needs supports can choose any provider. AAAs have contracts with providers, but people can use other providers.

Eligible caregivers may receive up to \$200 per month to help with out-of-pocket expenses ranging from respite care to incontinence supplies.

The caregiver and person who needs supports can choose any provider. Most expenditures will be considered for reimbursement if they can be justified as legitimate caregiving-related supplies, goods, or services. In addition, one-time grants of up to \$2,000 may be given to qualified families to modify the home or purchase assistive devices. Such adaptations might include installing a stair climb or modifying a bathroom.

Before a recent expansion enabled by funding from the U.S. Administration on Aging's National Family Caregiver Support Program, Pennsylvania's FCSP helped people who lived with and provided unpaid assistance to a relative (by blood or marriage) with physical and/or cognitive disabilities. For the family to be eligible, the person with a disability was required to be age 60 or older and unable to perform some of the self-care tasks necessary for daily living, or under age 60 with a physician's diagnosis of chronic dementia.

The new National Family Caregiver Support Program will enable Pennsylvania to expand the program to people helping non-relatives and to caregivers and people with disabilities not living together. Pennsylvania will also use the national program to help caregivers age 60 and older who are grandparents or other relatives of children age 18 and younger with the requirement that they be related and live

together. This component of the national program is at the option of the state and is limited to a maximum of 10% of the state and federal FCSP expenditures.

Implementation

FCSP began in 1987 in four counties as a demonstration project initiated by the Department of Aging. It was designed to evaluate services that the Department, through the state's county-based aging network, could provide to support primary family caregivers of people with disabilities age 60 or older or family members, under age 60, with dementia. The state legislature expanded the program in 1990, which provides statewide services through the state's 52 Area Agencies on Aging (AAAs). All AAAs implemented the program by 1992.

Publicity for the demonstration was channeled through hospitals, home health agencies, newspapers, various groups and clubs, health and county fairs, and senior centers. Challenges with implementing this program included identifying the needs of caregivers and helping them meet their real needs in ways that would support them and not cause more stress or burden.

Since FCSP reimburses caregivers directly for supplies and services, the program challenged AAAs to adapt to the needs of caregivers and older people with disabilities rather than the consumers conforming to a rigid set of benefits and services. AAAs were used to "wholesale"

The National Family Caregiver Support Program enabled an expansion and FCSP is "retail", in that each AAA was now reimbursing caregiver expenses on an individual basis rather than contracting with different providers to provide services.

Impact

The FCSP serves approximately 3500 families at any given time and about 6500 unduplicated families per year. It is funded from a combination of participant contribution and

through the state's general fund. Expenditures for FY 2001 through FY 2003 were \$11,461,000 annually. Costs average approximately \$2900 per family for a full year of stay in the program and the average length of stay in the program is a little more than eight months.

Some Discussion Questions

What is the impact of offering services on a sliding fee scale to people with too much income for Medicaid eligibility?

How can states coordinate and combine the supports available through a caregiver support program and Medicaid home and community-based services waivers?

Contact Information

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One of a series of reports by Medstat for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series will be available online at CMS' Web site, <http://www.cms.gov/promisingpractices>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.