

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

New Jersey – Statewide Respite Care Services

Issue: Flexible Service Package Focused on Informal Caregivers

Summary

The New Jersey Department of Health and Senior Services (DHSS) administers a state-funded, Statewide Respite Care Program providing a wide variety of services to relieve unpaid, informal caregivers from the stress of caring for older people and/or people with disabilities. The respite program customizes services to the person and the caregiver, with a focus on alleviating caregiver stress. Independent evaluations of the program have found that participants are highly satisfied with services provided.

Introduction

As the United States' population ages and medical advances allow us to live longer, the need for caregivers for older people and for people with disabilities increases. Meanwhile, the growing demands placed on informal caregivers exhaust available resources and support systems as people live with chronic disease and disability far longer than in the past. When spouses, adult children, friends, and neighbors become overwhelmed or are no longer able to support their loved ones, people often turn toward long term care institutions. The New Jersey Department of Health and Senior Services addresses this problem through a respite program that supports the needs of informal caregivers who are not eligible for services through Medicaid.

This report briefly describes the New Jersey Statewide Respite Care Program and how it supports informal caregivers throughout the State of New Jersey. The information herein is based on an interview with the program's senior administrator, and on two studies conducted by The Center for State Health Policy, part of Rutgers University's Institute for Health, Health Care Policy and Aging Research.

Background

Prior to the inception of the Statewide Respite Care Program (SRCP), New Jersey state staff were concerned with anecdotal accounts of

burnout among informal caregivers and the premature institutionalization of older people and people with disabilities. The state felt that it could coordinate the provision of supportive services to unpaid caregivers and help alleviate the stress of caregiving while improving the overall quality of life for both caregiver and person receiving support. Before the program's inception, there was no state program focusing specifically on the needs of caregivers.

Before the SRCP, no New Jersey program focused specifically on caregivers' needs.

Presently, the New Jersey Department of Health and Senior Services operates four other programs that provide respite services that overlap those provided under the SRCP: the Community Care Program for the Elderly and Disabled (CCPED), the Caregiver Assistance Program (CAP), Jersey Assistance for Community Caregiving (JACC), and the National Family Caregiver Support Program. Only CCPED was available in when SRCP started. The other three programs that provide respite services started in the late 1990s or the 21st century.

CCPED is a Medicaid home and community-based services (HCBS) waiver for older people and people with physical disabilities that provides in-home services. Individuals who are eligible for CCPED services may receive SRCP services if they have needs that cannot be met

through CCPED. CAP is the in-home services component of the state's other Medicaid HCBS for older people and people with disabilities, the Enhanced Community Options waiver. JACC is a state-funded HCBS program serving individuals who are not eligible for Medicaid or Medicaid waiver services. The National Family Caregiver Support Program is funded by the Administration on Aging, part of the U.S. Department of Health and Human Services.

Intervention

The primary function of the SRCP is to address the needs of caregivers and care recipients by lessening the burden associated with caregiving. The goal is to maintain caregiver health while delaying the institutionalization of the people who need supports. The program provides several services on a temporary, short-term basis to offer respite for the caregiver, including homemaker, home health aide, adult day care, companion, private duty nursing, and short-term inpatient care. Inpatient care refers to an overnight stay in one of several approved types of facilities, including licensed medical facilities, assisted living facilities, and alternate family care settings. All services are intermittent; the program does not pay for ongoing, daily services covered in other HCBS programs. Expenditures are limited to \$3000 per participant per year.

The day-to-day operations are managed and coordinated by 20 local sponsor agencies with whom the state contracts. The sponsor agencies act as advocates and points of contact for participants, contract with the necessary providers, and provide local oversight of providers. Sponsor agencies were selected through a competitive bidding process. About half of these agencies are home health agencies. Other agencies include units of county government, health systems, and hospitals. The agencies contract with a variety of providers, so participants have a choice of providers when possible.

A local agency in each county coordinates services and advocates for families.

Within each sponsor agency, one individual is selected as a respite care coordinator for that particular county. The coordinator provides flexible, customized assistance to caregivers with the intention of maintaining the caregivers'

health, so that the caregiver is better able to handle the complications and demands of caregiving.

Participants must meet both financial and functional eligibility requirements to qualify for the respite program. Financial eligibility requirements are less stringent than Medicaid requirements (for 2003, income of \$1,656 or less per month, \$3,312 for married couples, and liquid assets less than \$40,000). Families are responsible for 5% to 25% of costs, depending upon the families' monthly income. The county sponsor agency is responsible for determining eligibility. Agencies may employ a social worker or nurse, or contract out for the assessment.

The only functional requirement to qualify for the program is that the individual have a chronic mental or physical condition. An individual does not need to be nursing facility-eligible in order to utilize the SRCP. The assessment is primarily concerned with the stress level of the caregiver, which does not always correspond directly to the number of tasks performed or level of disability of the care recipient. The majority of assessments are conducted in the participant's home, allowing the assessor an opportunity to evaluate the participant's stress level in the context of their everyday living situation.

Implementation

The SRCP is a stand-alone program funded by New Jersey's Casino Revenue Funds. The SRCP started in 1983 as a demonstration program in a few New Jersey counties, partially financed by the Centers for Medicare and Medicaid Services (then the Health Care Finance Administration or HCFA). After a 1987 evaluation of the demonstration indicated positive results, the SRCP became statewide in 1988.

In many New Jersey counties, the SRCP sponsor agencies receive National Family Caregiver Support Program funds from the Area Agency on Aging (AAA) in their county. These funds allow the sponsor agencies to serve additional families under the SRCP or to serve families who are not eligible for SRCP, but need respite. Staff in the SRCP agencies coordinate with staff at the AAAs to ensure that families who need assistance are not falling through the cracks.

Many participants and caregivers learn about the program from hospitals, visiting nurses associations, and other points of contact. Participants and caregivers also learn about the program through NJ EASE, a toll-free hotline maintained by the state. Participants may also learn about the program through the Internet, through Area Agencies on Aging, and through the advocacy organizations for people with disabilities. The state pays for additional outreach as part of its contract with sponsor agencies; the nature of this outreach varies from county to county.

Impact

From 1993 through 1999, the SRCP served 7965 individuals. These participants were predominantly over age 65 (89.4%), female (70.4%), and coping with a late-onset physical disability or disease (71%). The annual program budget in state fiscal year 2003 is \$5.75 million.

Discussion Questions:

How does a focus on the caregiver enhance or hinder the ability of this program to prevent institutionalization?

Many people who use this program would be eligible for Medicaid nursing home payment after several months in a nursing home. How can the state measure any cost-effectiveness benefits?

The qualitative evaluation published in September of 2001 found that both staff reports and family surveys confirmed caregiver relief and improved overall quality of life for both caregiver and the person receiving support. A 1992 study by Rutgers University's Institute for Health, Health Care Policy, and Aging Research found high caregiver satisfaction among people who used the program from 1988 through 1990. In initial interviews, 93% of those interviewed were either "extremely" or "somewhat satisfied." During follow-up interviews 18 months later, 88% were similarly satisfied.

Contact Information

For more information about New Jersey's Statewide Respite Care Program, please contact Rebecca McMillen, the program's Administrator, at (609) 943-3466 or rebecca.mcmillen@doh.state.nj.us. General information about an array of New Jersey's services for older people is available at <http://www.state.nj.us/health/senior/sraffair.htm>.

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.hhs.gov>. 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.