Rutgers Center for State Health Policy

The Institute for Health, Health Care Policy, and Aging Research

Respite Services in New Jersey's Community Care Program for the Elderly and Disabled

Report #2 of the Project "State-Sponsored Respite Care in New Jersey"

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December 2002

THE STATE UNIVERSITY OF NEW JERSEY
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Acknowledgements

We gratefully acknowledge the support of the Alzheimer's Association, which financed this study, and of the New Jersey Department of Health and Senior Services (DHSS), which provided data and facilitated additional data collection. We are particularly grateful to the project Advisory Committee, whose members gave extensive time and support to this effort. Local members included Patricia Burch, Supervisor, New Jersey Community Care Program for the Elderly and Disabled (CCPED) and Home Care Expansion Program, DHSS; Jean Cochrane, Community Organization, CCPED and Home Care Expansion Program, DHSS; Peri Nearon, Administrator of the Statewide Respite Care Program, DHSS; Barbara Fuller, Program Manager, NJEASE, Caregiver Support and Housing, DHSS; Eileen Doremus, Coordinator, Support Groups and Community Outreach Services for the New Jersey Alzheimer's Association; Frances Saltz, Intern, DHSS; Fred Brand, formerly Director of Program Services for the Greater New Jersey Chapter of the Alzheimer's Association; Jeanette Ellis, formerly Program Coordinator of the Central Chapter of the New Jersey Alzheimer's Association; Susan Lachenmayr, formerly State Public Policy Coordinator for the New Jersey Alzheimer's Association Public Policy Coalition; Rick Greene, formerly Program Manager for Wellness and Family Support, DHSS; Joel Cantor, Director, Center for State Health Policy; and Stephen Crystal, Associate Director for Research, Center for State Health Policy. National members of the committee were Katie Maslow, Director, Initiative on Alzheimer's and Managed Care, Alzheimer's Association, and Suzanne Linnane, formerly Specialist, State Policy Clearinghouse, Alzheimer's Association. Invaluable assistance with data analysis was provided by Mario Kravanja and Dorothy Gaboda. Lori Glickman provided additional assistance.

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EXECUTIVE SUMMARY

Introduction

This report presents the findings of a study of the respite service offered by New Jersey's Community Care Program for the Elderly and Disabled (CCPED). This research was commissioned by the national Alzheimer's Association, and carried out by the Rutgers Center for State Health Policy (CSHP) in cooperation with the New Jersey Department of Health and Senior Services (DHSS) and the Greater New Jersey Chapter of the Alzheimer's Association. This report accompanies an earlier report on New Jersey's Statewide Respite Care Program (SRCP).

This study of CCPED respite utilized two types of data: 1) interviews with program staff from the state and counties, carried out between November 2000 and May 2001, and 2) the program's computerized administrative data for respite users for the years 1993-1999. These data were utilized to describe the design and implementation of CCPED, with particular attention to the respite service, important program changes, perceived strengths and weaknesses of the program, the client profile, and service use patterns.

The following were key findings of the report:

Conceptual differences in SRCP and CCPED: Respite is one of eight home and community-based services offered through CCPED. As such, it takes on a different conception than in a stand-alone respite program like the SRCP. In the context of the stand-alone program, all services provided are understood to be respite, and respite is most likely to be used on a regular basis, as a form of periodic caregiver relief. In the context of CCPED's broad array and large volume of services, respite represents a more limited set of options than it does for the SRCP. It has generally come to mean something outside of the standard services, usually used in case of a caregiver emergency, vacation, illness, or another anomalous event. Not surprisingly, then, institutional respite is dominant in CCPED, as opposed to home-based in the SRCP, and clients are likely to have used only a few units of respite during their time in the program. Nonetheless, 653 clients had used respite in the seven-year period studied here, suggesting that it is an important stop-gap service.

Conceptions of SRCP and CCPED are different in two additional related ways. First, while the programs share the goals of relieving caregivers and preventing institutionalization, preventing institutionalization is primary for CCPED and caregiver relief is primary for SRCP. Second, the care recipient is considered the primary client in CCPED, whereas care recipients and caregivers are equally clients for SRCP.

Implementation strengths: County supervisors understand the CCPED program's goals, and differences between CCPED and SRCP respondents in program conception conform to the actual differences in the two programs' design and priorities just described. In pursuing program goals, CCPED respondents - like the SRCP staff - evidence flexibility and a client service orientation.

Implementation of the CCPED program shows a number of other strengths as well. Poorer segments of the target population are well-represented among program clients. Both county supervisors and DHSS staff are happy with intraprogram relationships, citing open lines of communication, timely responses to concerns, and strong state support of the counties.

Implementation challenges: Some challenges for CCPED also emerged in the study. Several CCPED respondents suggested that the program's emphasis on preventing institutionalization and their need to respect consumer autonomy might be leading them to provide services to people at home who are so debilitated as to be unsafe in the home setting.

Another concern for program staff - one familiar from the SRCP study - was the difficulty of finding service providers. In particular, home health aides are scarce and it can be difficult to find nursing homes that will take clients for short- term stays.

A bureaucratic challenge for many CCPED care management supervisors is the division of responsibilities between the care management site, the Long-Term Care Field Office and the Board of Social Services/County Welfare Agency. This division of responsibility can create delays and communication failures. In many cases, it means that care managers have no contact with clients once they are deemed financially ineligible for CCPED, thus eliminating the opportunity to refer clients to other programs, including the SRCP.

One way in which counties differed was in whether they maintained regular oversight of vendors. Supervisors could benefit from clarification of their roles and responsibilities in this area.

Special Child Health agencies face unique challenges in terms of the special needs of their clientele. They perceive an inadequate supply of providers with the specialized services they need. They also find the regional meetings with DHSS to be of less help to them than to the agencies who serve senior populations.

Perceived benefits: Supervisors perceive the CCPED program to have great benefits for clients. As with the SRCP, clients who were diagnosed as having a mental condition used services differently than clients with physical diagnoses. Also as with SRCP, interviewees perceived clients to

be coming into the program at late stages. Median duration in the program is relatively long compared to the SRCP, suggesting that late entry may not be as large a problem for CCPED. However, supervisors feel that the program could be of even greater benefit if clients entered the program earlier.

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Part I: Introduction

Overview

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The study presented here is a companion to a study of New Jersey's Statewide Respite Care Program (SRCP), a stand-alone respite program. That study was reported on in "New Jersey's Statewide Respite Care Program: A Study of Program Design, Implementation, Clients, and Services."

This study of CCPED respite utilized two types of data: 1) interviews with program staff from the state and counties, carried out between November 2000 and May 2001, and 2) the program's computerized administrative data for respite users for the years 1993-1999. These data were utilized to describe the design and implementation of CCPED, with particular attention to the respite service; important program changes; perceived strengths and weaknesses of the program; the client profile; and service use patterns.

Background

Program Description

CCPED began operations in October of 1983, as the result of a Medicaid waiver. The program's purpose is to help individuals stay in or return to the community rather than being cared for in an institutional setting.

CCPED combines four state plan services – medical day care, transportation, home health, and prescription drugs – and four Medicaid waiver services - case management, respite,

homemaker, and social day care. Funding is provided through federal Medicaid dollars and state casino revenues.

For program purposes, respite is defined as "a temporary service offered on an intermittent basis to persons primarily being cared for at home." According to written program documentation, the purpose of the respite service is to provide relief for family members or other caregivers by allowing a leave period to reduce stress and meet other personal needs. Respite can be provided in the home or in an institutional setting. In-home care is provided by a home health or homemaker agency, and can take the form of eight or twelve-hour periods, during the day or during the night, or twenty-four hours. Clients can use a maximum of fourteen days of in-home care in a program year. Institutional respite is provided in a nursing facility, and is limited to thirty days in a program year.

To be eligible for CCPED, individuals must be 65 or over and eligible for Medicare or have other coverage for hospital and physician services; under the age of 65, individuals must be determined disabled by the Social Security Administration or Division of Medical Assistance and Health Services, and have other coverage. Clinical eligibility is determined through a formal assessment process, and the program aims to enroll only clients who need a nursing facility level of care. Financial eligibility is based on the care recipient's income and resources and - if the care recipient is married -- the spouse's resources. As of December 1999, the income threshold was $1536/month; the asset limitation was $2,000 for a single person and $3,000 for a couple.

CCPED is administered by the New Jersey Department of Health and Senior Services' Office of Waiver and Program Administration. Locally, the program is primarily administered by sponsor agencies that contract with the New Jersey Department of Health and Senior Services for this purpose. In each agency, one individual is designated as the care management Supervisor for the program. Some of the case management sites offer state plan services, some offer waivers, and some offer both. There are 40 case management sites statewide.

In each county, two additional entities are involved in program administration: Long-term Care Field Offices (LTCFOs) and Boards of Social Services/County Welfare Agencies (BSS/CWA). LTCFOs conduct clinical assessments, technical advisement and review of long-term care plans. BSS/CWAs assess financial eligibility and establish a Medicaid account number for eligible clients. Each county is allocated a specific number of program slots, i.e. a maximum number of individuals who can be served in that county. As of 2001, the monthly cost cap for the program was $2,841. Because most clients do not require this level of expenditure, some slots are funded at 100% of the cost cap while others are funded at 70% of the cost cap.

Study

The main purpose of this study is to provide the Alzheimer's Association with a more complete picture of respite services for the elderly and disabled in the state.[1] In addition, the SRCP and CCPED programs provide an interesting comparison, with one being a stand-alone respite program and the other a broader program of community-based services. Finally, the study aims to provide useful feedback to CCPED on its operations, client profile, and service use. CSHP was commissioned to meet these objectives with the assistance of a project Advisory Committee, comprised of representatives of the Alzheimer's Association, DHSS, and CSHP.

Study Questions and Methods

To meet the objectives outlined above, this study addresses the following questions:

1. What is the program's design, including administrative structure, eligibility criteria and determination, service offerings and management, and outreach procedures? What is the program's philosophy?
2. How are administration, eligibility assessment, service management, and outreach carried out?
3. What are the perceived strengths and weaknesses of current program operations?
4. What are perceived as important changes in program design?
5. What are perceived as important aspects of the policy, market, and demographic context for program operations?
6. In what ways is there collaboration and competition with the SRCP?
7. Who is served by this program, including age, gender, income, caregiver relationships, and diagnosis?
8. What kinds of services are utilized, and by what kinds of clients? How are services bundled?
9. How has client satisfaction been measured, if at all?

To answer these questions, the study utilized two sources of data. First, we analyzed computerized administrative data of the program for 1993 to 1999. The data elements analyzed were:

- County of service.
- Care recipient characteristics: date of birth, gender, diagnosis, and income
- Caregiver relationship to care recipient
- Reason for application to the program
- Reason for termination from the program

- Enrollment date
- Termination date
- Utilization: Type and amount of services utilized each program year.

Second, interviews were conducted with two program administrators from DHSS (one current and one retired) and with eighteen county case manager supervisors. [2] These interviews addressed program design, operations, strengths and weaknesses, important changes, and contextual concerns. Semi-structured research instruments were generated based on the expressed interests of the Alzheimer's Association and DHSS, the methods and findings of a 1992 study of the SRCP,[3] and the input of the Advisory Committee. (See Appendix I for instrument.)

Ten of the eighteen agencies whose supervisors were interviewed are county government offices, such as the Board of Social Services (BSS). Home care agencies represent six of the agencies included in the sample. Four agencies were Special Child Health Service agencies focusing on the case management of families with children who are developmentally disabled. These agencies do not have a large caseload, with generally no more than five clients being served at one time. Nine agencies whose supervisors were interviewed served all of the CCPED clients within their respective counties. Others shared responsibilities either with county government offices or non-profit care providers (e.g. hospitals, home health care agencies).

Part II: Program Implementation and Outcomes: Perspectives of the Program Staff

Overview

Interviews with DHSS staff and county case management supervisors addressed program design, actual operations, perceived strengths and weaknesses, important changes to the program, and important changes in the policy and market context.

Administrative Structure and Staffing

Sponsor Agencies

The majority of supervisors believe that the nature of the sponsor agency affects the way the CCPED program is implemented. For example, one supervisor working for a county agency feels that a conflict of interest exists when a service provider administers the program; another thinks that being a county agency provides care managers with more community resources to serve clients and make referrals for those who are on wait lists. At BSS agencies specifically, supervisors cite the

unique advantage of having the county welfare office -- which carries out eligibility determinations -- in the same locale as care management. Hence, financial eligibility officers are within an arm's reach of the care managers. Says one case management supervisor, "I can contact intake and welfare officers. If I need something done in a hurry, I can put some pressure on them." Furthermore, this supervisor feels that this arrangement lends itself to continuity of case management. "Clients are managed by the same care manager who processes their application," she explained.

On the other hand, supervisors at home care agencies assert that they have better access to aides and nurses. Several supervisors added that all of the professional disciplines are housed by a home health aide agency (e.g. nurses, social workers). This provides a comprehensive resource base for the care managers. A DHSS staff person notes advantages to both provider agencies and county agencies. The former might have better access to service providers; the latter might have pools of other funding that it could use to help clients.

Special Child Health supervisors assert that they have particular strengths for serving their clientele. A supervisor explained: "The BSS might not have access to these resources [that the Special Child Health agency does]. They might not be able to identify and reach out to the families the way a special child health agency is in the position to do."

Supervisors and care managers

At the time of the interviews, the average tenure period for the supervisors was approximately 6 years, with a range of 4 months to 13 years. Most had experience in the implementation of a government program or with long-term care or both prior to assuming the supervisory role within CCPED; some had been care managers for CCPED.

Fourteen of the supervisors interviewed are social workers whereas four are registered nurses. Social workers and nurses offered different perceptions of the effect of the supervisor's background on the administration of the program; their reflections are similar to those of the SRCP county coordinators. For example, several social workers stated that they are more able to appreciate the social and behavioral conditions that play into the families' need for services. "Eligibility workers (nurses at the LTCFO) tend to look at the hard lines. Social workers take the family dynamics and client situations more into account." Other social worker skills cited include: ability to deliver goal oriented service, specific professional training on the development of care plans and a better awareness of the services available to the clients within the community. "I know where to get my clients eyeglasses for free," offered one individual. Similarly, several social workers feel that their training causes them to take a holistic approach to clients' needs -- looking at both social and medical needs -- and encourage the care managers to do so as well. "I am attentive to both people's social and medical needs. I supervise both RNs and social workers. I find myself encouraging

the RNs to look more toward the social needs as well as the medical needs of the clients and vice versa for the social workers."

On the other hand, several nurses noted that their medical backgrounds enabled them to perform thorough clinical assessments to follow up the assessment done by the LTCFO, to readily recognize changes in the client's physical condition, and to network with community health agencies.

Sixteen of the coordinators interviewed have responsibilities outside of the CCPED program. For example, several coordinators supervised one or more of the following programs: Adult Protective Services, the SRCP, Medicaid Model Waivers, Jersey Assistance For Community Caregiving (JACC), the Caregiver Assistance Program (CAP), and a few grant sponsored programs. There is a large degree of variation in the time spent by supervisors on the CCPED program. Excluding the special child health centers (who have very small CCPED case loads), eight supervisors devote between 20-30% of their efforts to CCPED, whereas six put in between 60-95% of their time. Four supervisors do case management for CCPED on top of supervising the other care managers. Six counties expressed the need for more staff (with care managers described as overworked), and three anticipate the need for more care managers once the expansion slots are completely filled. One individual noted, "We need more staff. The care management supervisor should not have 60 cases. I would like to only have to carry between 15-20 cases myself. Also, I have a care manager who has 84 cases! Ideally, one care manager should have about 65 cases." However, eight supervisors did not feel the need for more staffing. Finally, one supervisor did not express a need for more CCPED care managers, but would like a nurse to be on staff to conduct evaluations.

Consolidation of CCPED Agencies

CCPED is effectively run by three entities. The care management site implements long-term care plan development and case management. The Long-term Care Field Office (LTCFO) conducts clinical eligibility determination and provides oversight of the long-term care plan. The Board of Social Services/County Welfare Agency (BSS/CWA) determines financial eligibility and assigns Medicaid numbers. In approximately half of the agencies interviewed, the care management facility encompasses the BSS/CWA, LTCFO or both. One supervisor described the arrangement as "one-stop shopping consistent with the NJEASE initiative."[4] Supervisors expressed a few benefits of this arrangement including the ability of everyone involved in the management of the client to consult one another with relative ease, less confusion for the clients (senior citizens especially), and less confusion for the care managers, with all the information they might need about a client under one roof.

Program Conception

Primary Goal

In line with CCPED's stated goals, the overwhelming majority of supervisors and state staff described their primary goal as safely providing home-based services to the elderly and disabled to allow them to live in the community. A DHSS staff member explained, "CCPED's goal is to offer enough community alternatives to keep people out of nursing homes." Seven individuals opined that many clients certainly would be in a nursing home if this service did not exist. One supervisor asserted that her primary goal is to provide relief to the family and to alleviate the burdens associated with caregiving. Several people noted that the provision of home-based services and relief to the family go hand-in-hand. The primacy of preventing institutionalization for CCPED supervisors contrasts with the views of coordinators of the SRCP, who feel their primary goal is to provide relief to the caregivers with a secondary goal of preventing institutionalization. This difference conforms to the programs' distinct designs.

Logically, special child health providers tend to put more emphasis than others on rehabilitation and service to the family. Ways by which they feel that the CCPED program helps these families include physical rehabilitation of the children, other skill development for both the children and the families (e.g. coping skills) and relief to the families in the form of some independent time. One supervisor noted, "The break makes life more livable for these parents."

The vast majority of supervisors feel that both the clients and the other agencies working to serve the families (e.g. service providers, long-term care offices) share the objective of preventing institutionalization. One supervisor comments, "They (other state offices) are accepting the aging population and the concept of keeping the elderly in the community in recent years. The clients come to us asking about the program." Only one individual feels that the community is not well aware of the CCPED program or the services that are provided through it.

Primary Client

When asked whom they consider to be the primary client of the program, more than half of the respondents considered it to be the care recipient. Again, in line with the programs' designs, this perspective contrasts with that of the SRCP coordinators, who mostly share the viewpoint that the caregiver is the primary client. According to one CCPED supervisor, "Everything revolves around keeping the client in the home. I have placed clients in nursing homes to get them desperately needed care, so that they may remain in their homes later on for a longer period of time." She further added, "I will interview the care recipient first if appropriate to determine his or her needs, then I will take into consideration the family preferences." Six coordinators believe that the whole family is the

primary client. "The service is rendered to the care recipient, but the whole family is being served as one unit."

The Implications of Mission for Work

Coordinators described numerous ways in which their perceptions of the program's goals affect the way in which they conduct their work. Often this was particularly apparent in how coordinators dealt with the challenges of their jobs. Most supervisors provide combinations of service that meet as many of their clients' needs as possible. For example, one supervisor explained that she has to combine services to overcome the limitations imposed by the shortage in homemakers. Supervisors often describe their role to be that of an advocate. "I advise my clients how to use services effectively and wisely, such as a respite when a vacation is needed." Furthermore, another individual added, "I am flexible with my definition of a caregiver. I will allow a caregiver to take a respite even if they do not live in the home with the caregiver, rather live in close proximity."

The linked issues of appropriateness of service and client safety were regarded as highly important by several supervisors. "Safety must be taken into consideration when providing care for the chronically ill." Several coordinators expressed a concern that the CCPED program should reconsider its efforts to maintain some of the more debilitated clients in the home setting, as it is an unsafe situation for both the care recipient and the care providers. One individual offered, "I sometimes have a problem with the types of patients that the LTCFO puts on the program. There are some clients who have been sicker than they have been in the past, and they might be better served on other programs. Perhaps a more thorough assessment is needed to avoid this breakdown." One supervisor explained that the state's emphasis on preventing institutionalization has led some agencies and supervisors to believe that institutionalization must be prevented in all situations where it is possible, arguing that sometimes assessors and care managers are unable to draw the line and deny a family service through CCPED. Another supervisor expressed her concern for the caregivers: "Caregivers are often old and ill themselves, so I try to keep in mind what is most healthy for both the caregiver and care recipient." DHSS staff note that there is a difficult balance to achieve between consumer safety and respect for consumer autonomy; clients cannot be forced into nursing homes against their wills, and have the right to make their own choices and take their own risks.

A serious concern of the Special Child Health care managers is the lack of service programs that are specifically geared toward children. One supervisor commented that some desperately needed services are not paid for by the program (e.g. the $50 limit on medical supplies). Furthermore, she feels that the program offers a false sense of hope by accepting a family, designing a care plan and then being unable to provide services because she cannot find an available aide.

Changes in the Program's Goals

The overwhelming majority of supervisors did not perceive any changes in the mission or philosophy of the program in the time that they had been associated with it. One supervisor, however, noted that the state has pushed harder to prevent institutionalization of the elderly and disabled. As noted earlier, several supervisors are concerned that such a push maintains severely disabled clients in the home who may be a danger to themselves and potentially to the providers entering the home.

Respite Service as a Component of the Long-term Care Plan

The majority of supervisors defined respite service as it is stated in the CCPED manual. However, a few individuals noted that it can be confusing determining what "respite" is when an individual is receiving a gamut of formal services that preempt some of the need for informal caregiving.

Most supervisors cited a change in the caregiver's situation as the primary impetus for utilizing respite services. For example, caregiver illness, a caregiver's need for a vacation and signs of caregiver burnout (noted to be physical exhaustion, a sense of being overwhelmed, etc.) were among the common scenarios warranting respite care. One supervisor offered, "Sometimes we encourage a caregiver to take a break. If we lose a caregiver, we have a mess on our hands." Another supervisor explained that respite allows time for the promotion of the caregiver's well-being: "The health of the caregiver is very important, especially if they are spending twenty-four hours with the client." Although there is no formal assessment of the caregiver, supervisors generally feel that the care managers can easily assess the level of tension during a home visit. In addition to caregiver needs, one supervisor volunteered that the agency uses respite to piggyback on CCPED traditional services in order to offer recently discharged clients more service when necessary.

A DHSS staff person commented that respite is included in the package primarily in situations where the caregiver is removed from the home for a period of time that would otherwise cause the care recipient to be admitted into an institution.

Counties seem to vary in how they address respite in planning. Many supervisors noted that they explain the details and utility of the respite service upon meeting with primary caregivers initially, especially when the caregiver is caring for a dementia client, works full-time, appears overwhelmed or is raising children. One supervisor added, "The working caregivers are the ones who actually use the service. They do realize that it (caregiving) is too much to do alone." Some will work respite into the formal plan to make it more convenient and easier to access a provider when respite is actually needed. A few supervisors explained that vacations are always planned in advance in order to gain a firm nursing home spot for the care recipient. Others incorporate respite into the plan when

a situation arises that calls for respite service (e.g. caregiver emergency). Interestingly, one supervisor does not encourage her case managers to push institutional respite care because she feels that seniors tend not to fare well outside of their environment for a whole month. In her opinion, the experience promotes disorientation and complicates the reclamation process. Out of the fourteen agencies interviewed that are not special child health facilities, eight report that 20-30% of their caseload use respite services, and six agencies have greater than 50% using respite. The supervisors reported that approximately 50% of care recipients have live-in caregivers, excluding the special child health agencies (which of course all have live-in caregivers).

The majority of the special child health supervisors interviewed have not accessed respite for their clients. One supervisor elaborated that her families are afraid of institutional placement, both due to their unfamiliarity with facilities and the young age of their children. Lack of familiarity with providers also is reported to deter families from allowing aides to come into the home for a prolonged period of time (e.g. overnight care). However, if a family were comfortable with the arrangement and respite was appropriate, this supervisor would offer it as an alternative to a family that needed a reprieve from the home setting.

It is important to note that the inclusion of respite service formally into the long-term care plan in no way places the family under an obligation to use these services. For example, every supervisor agreed that clients can change their care plans quite easily as long as the providers and funds are available to accommodate the change. Furthermore, several supervisors described their care managers as taking on a personal role in attaining the services needed by the family in the face of changing circumstances or needs. "A client's crisis becomes our crisis if a modification needs to be made to the plan," offered one supervisor.

Intraprogram Relationships

Supervisor Relationships with the LTCFOs

Approximately half of the supervisors described the LTCFO as maintaining a good working relationship with the care managers. For example, care managers might refer to this office for information pertaining to the wait list or information on a particular client's eligibility status. One coordinator noted, "The common goal is to get the client into the program." Others described the relationships as difficult. One supervisor explained, "Care plans are mailed off and we pray that it will come back signed. We don't have that personal contact anymore. There is so much turnover, that we don't know who we are dealing with." Another supervisor added that the LTCFO in her county is understaffed and overworked, hence explaining their difficulty returning care plans in a timely fashion.

Furthermore, a few supervisors mentioned some changes in this relationship over time, such as enhanced communication with the nurses conducting initial assessments when the LTCFO moved closer to the care management site. A positive change according to three people was the elimination of case conferencing involving the physician, nurse, care manager and LTCFO officer. "The process (case management) is more streamlined now, thus allowing the care manager to make decisions without having to case conference," according to one of these supervisors. She further elaborated that this allows her care managers to spend more time on their duties.

Suggestions for improvements by a few supervisors included dual clinical assessment by a social worker and a RN. One supervisor elaborated that dual clinical assessment might enable the "team" to better determine which clients are inappropriate for home-based care. "The LTCFO should have the authority to refuse service to clients."

Supervisor Relationships with the BSS/CWAs

There were mixed reports regarding the level of communication between the care management site and the BSS/CWA, dependent largely on the proximity of the office. For example, four supervisors either work in the same building or in close proximity to the BSS. This was described as contributing to good communication and ease of contact. In one county, the same supervisor who determines financial eligibility performs care management.

In contrast, a few supervisors feel that their BSS/CWA is disorganized and overburdened. "There has been a general lack of concern to expedite client applications; they (BSS/CWA) focus on their own burden rather then updating us on our cases," explained a supervisor. There have been delays in the assignment of Medicaid numbers to clients, creating problems for provider reimbursement and client service provision. Furthermore, another coordinator described the BSS/CWA as failing to understand the needs of the clientele. "They either don't understand or have lost contact with elderly people and the issues that they face. For example, the CWA kept sending papers out to one of our clients who was blind without trying to help her understand the material." Finally, two supervisors mentioned an occasional communication breakdown between the BSS, the care management site and the LTCFO.

When asked about referring financially ineligible individuals to other programs such as SRCP, many supervisors explained that because of the BSS/CWA's responsibility to determine financial eligibility, they are not informed when clients are deemed financially ineligible. In these cases, the onus would be on the BSS to refer them to the appropriate program. The supervisors feel that the BSS is knowledgeable regarding community resources and could perform the referral role. There are other supervisors, however, who do learn about ineligible clients, either because BSS initiates contact, because they have ongoing communication with the BSS by virtue of sharing the

same roof, or because clients inquire directly to the case management office. A few supervisors do take advantage of other options at their disposal or rely on the BSS to refer them to another program, for example, sending clients to grant programs that can provide CCPED-ineligible clients with homemaker services or referring clients to the SRCP until they become eligible for CCPED.

DHSS staff are hopeful that current reorganization within their department will help to promote better coordination throughout the state.

Supervisor Relationships with DHSS

Overview

DHSS holds one meeting a month with the program care managers. The state is divided into four regions, and monthly meetings rotate among the regions, so that each location has three meetings per year with DHSS. As reported in our interviews, these meetings are a key component of DHSS contact with the supervisor. However, more than half of the interviewed supervisors have contact with the DHSS in addition to the meetings. Six supervisors find themselves initiating contact on at least a weekly to monthly basis. The majority of supervisors said they use this contact to clarify rules and regulations of the CCPED program. Other issues prompting communication are questions related to billing, client petitions, and special service requests.

Major strengths of the existing relationship as cited by supervisors and DHSS administrators included open lines of communication, timely responses to concerns, knowledgeable state support staff and DHSS's willingness to help. A supervisor explained, "Everyone has their hands full. There might be a lack of knowledge on the parts of the care management sites at times. The DHSS has been very understanding and has served as a resource." One supervisor asserted that communication has become 100% more effective over the last couple of years since a change in the DHSS administrative personnel took effect. With regard to oversight of the care management facilities, a DHSS staff member explained that the DHSS maintains oversight by remaining in regular contact with the various sites.

Meetings

More than half of the supervisors attend the quarterly meetings regularly, finding them to be helpful. Both DHSS staff and county supervisors feel that the meetings have improved intraprogram communications. Supervisor noted that the meetings serve to inform the counties of changes, such as new services or players at the state level or new local service providers; allow staff to share ideas; promote the voicing of concerns; and provide the opportunity for questions. A DHSS

staff person states, "I work to inform the supervisors quickly of changes in policy." A county supervisor comments, "Exposure to your counterparts and state officials facilitates the establishment of professional contacts important to performing the intercounty management of clients." Some of the supervisors managing special child health services exclusively explained that they do not attend meetings regularly due to the focus on the adult population and the small CCPED caseload maintained through their agencies. One of these supervisors further explained that more material relevant to special children would make the meetings more useful to her and her staff.

Relationships among Supervisors

A substantial number of supervisors do not contact their counterparts in other counties regularly as they do not feel that such contact is necessary to do their work. However, a few supervisors noted that communication allows them to share information. "It is good to know that everyone is on the same page." Issues that prompt contact include transferring clients from one county to another and using service providers who are in proximity to county borders.

Eligibility Determination

Application Process

The LTCFOs are currently working on amending the CCPED application process. At the time of this study, eight supervisors felt that the application process necessary for enrollment into the CCPED program could be tedious and somewhat overwhelming at times. "A lot of information needs to be provided by the clients, especially for the financial eligibility section," noted one supervisor. She further explained that clients should be notified ahead of time by phone as to exactly what materials they should prepare prior to visiting the BSS. Also, those materials should be outlined in a letter that follows such a phone call. One supervisor described the application process as particularly difficult for elderly clients. Another said: "There are families who are under a lot of stress and they don't have time to fill out documents. To get through the CCPED application process you have to be an assertive, intelligent individual."

A few supervisors described the application process as a challenge to their care managers in their attempt to complete their responsibilities. For example, one care manager noted that the process necessitates additional assistance from the social workers, as some people have trouble with the questions that are asked, and accurate responses are critical for acceptance into the program. In addition, the process was described as being redundant, considering that many of the clients have

provided the same information to the BSS for other state programs. One supervisor stated, "The application process needs to be simplified."

With regard to the time necessary to process applications and enroll accepted CCPED applicants, supervisors reported a waiting period that ranges from 1 to 8 months. Variables that are reported to influence this period include BSS and LTCFO application processing, staffing shortages, current workload at the case management site and failure of the applicants to provide all required information. A DHSS administrator discussed the need to continue to work toward minimizing or even eliminating the waiting period from acceptance to service provision. This individual asserts that the waiting period can be eliminated through the education of those involved in the eligibility determination process, long-term care plan approval, and care management processes as to the nuances of the CCPED program.

Financial Eligibility Criteria

A few supervisors feel that the asset limits used in determining financial eligibility for the CCPED program (currently $2000/client) should be raised to a level similar to other state programs (e.g. JACC at $40,000 for an individual and $60,000 for a client, and SRCP at $40,000). However, one of these supervisors did comment that such an increase could potentially bring more clients to the CCPED program than they can accommodate.

Developing a Long-Term Care Plan

The majority of supervisors concurred that the needs of the care recipient, caregiver and family are all taken into consideration when deciding upon a specific service plan. Many of these supervisors explained that the views of the care recipients, especially those related to their medical conditions, are considered primarily if the care recipient is alert and oriented. The support systems that are in place play a role in determining which services are most appropriate for the family. For example, care managers look at resources available to the family (e.g. family members available to help out), the time the care recipient is home alone, the extent that the caregiver can care for the care recipient, and the climate of the home situation (e.g. relationship between the caregiver and care recipient).

Care managers working with families of disabled children seek specifically to understand the factors affecting the parents' abilities to care for their disabled child. Such factors include the work status of the parents, the number of hours the parents are out of the house, other young children within the household, and additional resources utilized by the family. Parents of child clients

tend to be especially involved in the planning process. In some instances, parents will independently research service options.

Client Budgets

Utilization of 70% and 100% Allocations

In the majority of counties represented in the interviews, it was reported that less than half of the clients who are at the 70% funding level are taking full advantage of the funds allotted to them, either because they do not need that level of service or because they encounter a shortage of available providers to meet their needs (e.g. homemakers). Similarly, half of the supervisors explained that the overwhelming majority of clients at the 100% level cannot spend all of their budget due to the home health aide shortage, whereas half described complete utilization. One supervisor noted, "This group is especially disabled and needy; they need a lot of home care." A special child health supervisor believes that her clients do not take full advantage of their budgets, because CCPED does not offer enough services appropriate for them. Illustrating the provider shortage, another special child supervisor described a guardian who seeks out aides and brings them to approved providers so that they can serve her child.

Supervisor Perspectives on Current Budget Levels

Approximately half of the supervisors feel that the current budget levels should be increased. A concern mentioned by several of them involved the recent increases in the case management fee ($75 to $95) and homemaker rates ($14.00 to $14.50) without a commensurate increase in the clients' budgets. "Although I feel that case management fee is warranted as my care managers provide more than $95 per month in service to our clients, the increase in the fee takes away from the services to be provided to our clients," explained one supervisor. Another supervisor supported this notion: "It is terrible to take away services from our clients, even if it is only 1 hour a week." Supervisors were especially concerned about the clients who are at the 100% level. In addition to the fee adjustments, one supervisor noted that her care managers would like to see a budget increase to accommodate more than 14 days of in-home respite care for their clients

The other half of the supervisors felt that the current budget allotments are adequate, especially compared to those of other Medicaid Waiver Programs. However, several expressed the concern that although the budgets are sufficient, there are not enough aides and providers to utilize these funds and meet the clients' needs.

Moving clients from the 70% to 100% levels when needed does not appear to be a problem. A few supervisors described being able to increase fund allotments on a short-term or prolonged basis if there exists a need for increased service.

Program-Client Relationships

The overwhelming majority of supervisors spoke of a positive relationship with their clients. Several coordinators described a close relationship, with the staff members serving the clients' best interests and the clients comfortable with the staff. "care managers become part of the family," explained one. The supervisors generally concur that the care managers foster open lines of communication and emphasize a client-oriented relationship such that the clients view them as resources and turn to them for help. A DHSS staff member added, "The Case Manager is the person that is there for them." One supervisor commented that clients are happy to let the care manager handle arrangements.

There is some client dissatisfaction with the program and several supervisors attribute this disappointment to cardinal misconceptions. For example, some clients were described as feeling entitled to receive services without an understanding that provider availability is limited. Other clients do not fully understand the roles of the providers and their limitations with regard to service provision. For example, one supervisor described clients who insist that aides and homemakers extensively clean their homes. She explained, "Sometimes the clients think they are getting a maid rather than an aide."

Disadvantages with the program-client relationship include strong emotional ties to the clients that are emotionally taxing for several supervisors. In addition, a few supervisors are disappointed that they cannot always satisfy their clients' simple needs (e.g. sufficient aide hours). In addition, one respondent described reluctance among clients to report complaints due to a fear of losing services or some other type of punishment. Consequently, Case Managers may not always get the complete picture with regard to service satisfaction.

Outreach and Advertising

As described by a DHSS administrator, there are two types of advertising for CCPED: local advertising that varies depending on the resources and philosophy of the county and a state web site (including a mechanism for receiving concerns/questions). Approximately half of the supervisors perform outreach through providers and centers catering to the senior citizen population. Hospitals, clinics, home health aide agencies, Office on Aging, churches and senior citizen housing complexes

are among the venues that supervisors target for outreach. One supervisor encourages CCPED service providers to refer private paying clients who might be eligible for the CCPED program. She explained that the additional hours provided by the CCPED program would compensate for the differential between private and Medicaid reimbursement rates. "This arrangement brings in more revenue for the provider and better serves potential CCPED clients," commented the supervisor. Interestingly, supervisors who do outreach through providers perceive different levels of awareness of CCPED among health professionals in their communities. A few feel that their community is well informed about CCPED, whereas others communicate with health professionals who have never heard of CCPED. "The program has been around since 1986 and there are still doctors and hospital personnel who do not know about CCPED. These providers should have this information." This supervisor further recommended a more extensive dissemination of pamphlets and literature advertising the CCPED program to community health centers. In addition to focused outreach, one supervisor takes advantage of local radio and cable television services to advertise the program.

Logically, Special Child Health Services supervisors employ a family directed approach to enrolling clients in the CCPED program. For example, one supervisor utilizes the state birth defects registry to contact families within her region who might qualify for and benefit from CCPED's resources. Another supervisor monitors families enrolled in other state developmental disability programs in order to identify candidates for CCPED.

Half of the supervisors who do not undertake any specific outreach initiatives rely on the state for advertising and referrals for their client base. Two supervisors noted that the NJEASE program does an adequate job of informing their communities about CCPED. Another supervisor explained that she does not supplement the state's outreach efforts because she does not have access to providers who can accommodate new clients. She noted: "It is very frustrating to offer a family admission to the program without being able to provide the service."

Wait List

About half of the supervisors reported that they currently are carrying no waiting list or a rapidly evaporating one due to the expansion of slots for each county and additional state programs that have lightened the preexisting CCPED wait list.

Services

Service Availability

The overwhelming majority of counties reported having available all services advertised by the CCPED program. Five counties noted that they do not have access to one of the following services within their county: skilled nursing, social day care, home health aides local to their clients' residences, medical supply provider or medical day care. All of the above counties occupy the lower third of counties ranked by population density. This conforms to our findings on the SRCP [Silberberg and Caruso, 2001].

On a related point, almost all of the supervisors reported some degree of difficulty in providing service to the more rural areas of their counties. Specifically, the difficulty arises due to the long distances required to reach clients who live in more remote locations, the lack of reimbursement for an aide's travel time and inadequate public transportation servicing these areas.

Choosing Service Providers

Most supervisors describe choosing providers who can provide adequate and consistent service to their clients, an important consideration given the provider shortages (especially home health aides). Several supervisors make attempts to match their clients' preferences, location and specific needs (e.g. skilled nursing) with the providers available to serve CCPED clients. In a few counties, a plethora of providers are available. Supervisors in these counties reported that they choose among their providers equitably.

Competition and Turnover among Service Providers

Few supervisors see much competition among their service providers. Several supervisors explained that the competition for CCPED clients has decreased dramatically over the past decade to the point where CCPED is now seeking providers to service their clients. One supervisor attributes the lack of competition to the low Medicaid reimbursement rates. Another mentioned that there are many clients covered by other state programs, thus decreasing the need for providers to come to CCPED looking for business. One interviewee added, "There is no competition because there is so much need. If a client is not eligible for CCPED, it is good that they can get services elsewhere. CCPED has lists and lists of people wanting and needing services. Let's have more services." In contrast, three counties reported that in their communities agencies are desperate for clients. Some agencies will go as far as sending representatives to the CCPED office to market their services. One supervisor explained that the lower income population within her county presents

a market with few private-paying clients. Hence, providers actively seek the business of the clients covered under Medicaid. It is worth noting that all three of these counties represent the upper third of counties ranked by population density. Interestingly, they also fall in the lower third of counties ranked by median income.[5]

Most supervisors do not see much turnover among their service providers. The majority of the turnover that does occur is described as resulting from providers going out of business rather than dropping coverage to CCPED clients.

Oversight of Vendors

The majority of supervisors perform oversight of their providers by communicating with the care recipients and/or family, visiting the home and/or provider site while the care recipient is receiving service or contacting the administrators of provider agencies directly. Although most supervisors described a readiness to respond to client complaints and concerns, several supervisors do not maintain any regular oversight. One supervisor argued that the state should assume more responsibility in the oversight process by implementing more stringent regulations for provider licensure. In addition to CCPED initiated oversight, almost all of the supervisors mentioned the checks by nurses of home health aides performed in accordance with state regulations.

Most Effective Services

While the focus of our study was respite, we did want to understand how it fit into the overall package of services provided through CCPED. Therefore, we asked which services seemed most effective for clients and what additional services might be needed. Every supervisor and central staff member who was interviewed reported that homemaker or home health aide services work the best for their clients. They described these services as effective providers of social interaction that meet the clients' most basic needs (e.g. performance of ADLs). A supervisor explained: "Most of my clients are unable to perform their ADLs without the help of their aides." Day care, inpatient services, non-medical transportation and the pharmaceutical option are also perceived to be highly effective services by supervisors and central staff members alike. Day care gets clients out of the home and socializing, and medical day care offers the comprehensive medical attention. "It gives our clients something to look forward to," noted one supervisor. The pharmaceutical option aids seniors in the purchase of their costly prescription drugs, thus relieving them of a major financial burden. The majority of supervisors base their views on personal communication with clients and observations made during assessments.

Unmet Service Needs

The majority of respondents perceive that the CCPED program offers the services their clients need, but a provider shortage can make them unavailable at the level requested by clients. Supervisors were particularly concerned about the limited availability of homemaker and home health aide services, especially for meeting requests for 24-hour in-home respite. Similarly, several supervisors experience difficulty finding nursing homes that are willing to accept clients for short stays (e.g. the 30-day respite period). Both the homemaker/home health aide shortage and the difficulty of finding nursing homes for short stays were problems for the SRCP as well. An additional problem for CCPED is that a number of supervisors report being unable to find provider agencies that will accept the $50/month medical supply allowance in order to provide clients with needed materials. Special child health supervisors especially noted this to be a problem, as the use of this allowance offsets the costs of necessary supplies (e.g. diapers). Along the same lines, a few supervisors cannot find providers that can offer non-medical transportation for their clients, which places limitations on the number and type of services that their clients can access. In addition, a DHSS administrator would like to see over-the-counter medicine as well as cleaning services considered for inclusion in CCPED services. "A number of clients do not have caregivers living in the home. They would greatly benefit from a cleaning/chore service."

A couple of supervisors would like service options to include some of the benefits offered by other state programs such as JACC and CAP. For example, the CAP program allots more funds for medical supplies and covers doctor visits as well as hospital stays. Furthermore, both the CAP and JACC programs pay qualified friends or family members to serve clients.

Relationship between the Providers and the CCPED Program

Supervisors and central staff report overall satisfaction with the relationship that exists between the service providers and the program. Many supervisors believe that providers are trying hard to accommodate CCPED clients. Of the numerous strengths of these relationships enumerated by the CCPED supervisors, open lines of communications came up most frequently.

A few supervisors described situations where providers had failed to communicate vital information (e.g. a change in a client's condition). "It is important that my care managers know exactly what to expect from our service providers," according to a supervisor. According to one interviewee, "There probably is the least communication with the service providers." This individual recommends that care management sites work to keep providers in the loop on program policy decisions. "The best way to do this right now would be to invite providers to a central location and do presentations."

Relationship between the Providers and the Clients

According to the supervisors and central staff, the vast majority of service providers maintain positive relationships with the clients. A number of supervisors make efforts to mediate the relationship between clients and their providers. Overall, most supervisors agree that open lines of communication are maintained between the providers and the clients. In addition, a supervisor noted that the nurses who are sent out to the homes maintain an interface by which the care managers can receive information on the client and stay apprised of their status.

Advantages to good provider-client relationships were noted. First, the relationship maintained between the client and the home health aide can reflect on CCPED as well as the service provider. "Dependable and professional aides make a difference on the clients' impressions," according to a supervisor. Second, home health aides are in a position to provide continuous care. One supervisor reported a client who had an aide for many years. When the aide's employer stopped providing care to CCPED clients, the aide and the service provider agreed to work out an arrangement with another CCPED provider such that the aide could continue servicing this client under CCPED coverage.

On occasion, some supervisors field complaints from the clients concerning providers. Personality conflicts, breaks in continuity of care, and client expectations that are not being met are the most common sources of dissatisfaction on the part of clients.

Changes

Respondents were asked what changes they had found to be most important in program design, the implementation of CCPED at their specific agencies, in the national and state policy context, and in the long-term care market.

Program Changes

The majority of respondents cited the increase of slots (traditional in '93 and expansion in '98) and the addition of the pharmaceutical option in October of 1999 as the most significant program changes. One supervisor noted that these changes demonstrate the state's commitment to addressing unmet need. The addition of the pharmaceutical option has been described as representing a huge cost savings for the clients. Additional program changes seen as important and positive include the removal of cost share (mid-'80s) and a current initiative to consolidate paperwork that contains shared information among state programs. An increase in allowable cases per care manager from 55 to 70 in 1999 was seen as important but negative by a handful of supervisors, with one supervisor asserting that no care manager can be expected to adequately manage a caseload of 70 clients. [6]

Reactions were mixed to reimbursement fee increases implemented recently for both case management and homemaker services. Case management fees were increased from $70 to $95 per case. Homemaker reimbursement went from $14.00 to $14.50 per hour. Several supervisors do not expect that rise in the homemaker rate to make a substantial difference for the aides or attract new aides into the program. Although many supervisors feel that the increase in the case management fee from $70 to $95 will make a difference, they are uncomfortable with the idea that client budgets will have less money for services after case management has been paid. One respondent argued that the client budgets should rise together with the rate increases, so that the clients are not penalized for the rate hikes.

Changes in Agency Operations

When asked about important changes in their agencies' operations, a few respondents mentioned the combining of care management and financial eligibility roles within a BSS agency. One supervisor offered: "This way care managers open the case during the financial review stage and manage the client straight through. There is less confusion for both parties involved." A negative change noted by a supervisor was recent cuts in her agency's budget that forced her to hire and maintain bachelor's level social workers exclusively, as RNs are too expensive.

Changes in the State or National Policy Context

In respondents' view, the most important policy change has been the creation over the past couple of years of the constellation of programs known as the Senior Initiative, having both positive and negative implications. A few supervisors described the NJEASE initiative as setting up the state for a potentially overwhelming situation when the multitude of options being offered becomes unmanageable. On the other hand, four supervisors asserted that the waiting list for CCPED was reduced as a result of the recent advent of state programs such as CAP and JACC. Furthermore, a couple of supervisors feel that the existence of JACC and CAP offers care managers the option to transfer clients into these programs when the service options are appropriate for the clients' needs. Effectively, this both increases available resources and allows the care manager to target services to the client populations that are best served by them. In addition to the new New Jersey programs, a DHSS administrator cited the impact of the Olmstead decision, in making the reduction of the CCPED wait list a major priority across the state.

Changes in the Long-Term Care Market

A substantial number of supervisors complained about the current homemaker/home health aide shortage. "The demand for aides is increasing while the pool of available providers is shrinking," explained a supervisor. In light of this disparity, supervisors think it is a problem that the state is rolling out new home health programs without taking serious steps to remedy the homecare provider crisis. Suggestions to address this problem include a substantial increase in the reimbursement rates, education for the aides to help them better cope with different personalities in the home (to reduce turnover), and the provision of better public transportation to facilitate travel to the more remote county locations. In addition to the growing home health aide shortages, two supervisors believe that nursing homes are not setting aside enough guaranteed beds for respite clients.

Many respondents speculated that the advent of assisted living has had a mitigating effect on the CCPED wait list, although one argued that clients still wish to remain in their home and continue to seek the services offered by CCPED. In fact, she argued, the demand for home and community-based services is increasing. "People want to stay home despite the fact that there are now more assisted living facilities coming up. So, with many caregivers and care recipients wanting to maintain the home care situation, coupled with an increase in the number of seniors seeking services, the CCPED program is being pushed to do more."

Pertaining to special child health, one supervisor explained, "Fewer and fewer providers have been jumping into this arena, thus leaving less options to treat the kids." Another special child health supervisor described her provider availability issues as specific to overnight facilities and specialized services. She explained, "There are not enough incentives to attract service providers to come on board and serve CCPED clients."

Relationship between the Statewide Respite Care Program (SRCP) and CCPED

Respondents were asked a series of questions about interactions between CCPED and the Statewide Respite Care Program (SRCP). The majority of CCPED agencies collaborate with SRCP to make sure that clients are covered while on a wait list for CCPED or during a period of ineligibility - if they know that the client is ineligible. A few respondents also noted that they can take advantage of provider resources that might be used regularly by the SRCP program in the county but not the CCPED program (e.g. a nursing home that accepts respite patients at the last minute). While some respondents couldn't make referrals for ineligibles because they never knew about them, some agencies (typically the smaller ones) had specific arrangements with SRCP that allowed them to refer clients. The special child health programs do not have much contact with SRCP, as children are not

eligible for that program. But one of the special child health supervisors noted that she collaborates when SRCP has access to resources that would be useful to her clients (e.g. a facility that accepts pediatric placements for extended stays).

In addition to these forms of collaboration, several supervisors coordinate their service plans with SRCP coordinators to ensure against duplication of services. There was some confusion about the legality of providing services to a client through both programs. The rules state that services cannot be offered under Medicaid if the *same* services are being administered by another program. The overwhelming majority of supervisors expressed that it was illegal to be on both programs unless one program is meeting a need that the other cannot satisfy. However, a couple of supervisors were not sure if there were any formal regulations prohibiting the duplication of services and one supervisor described duplication of services as legal.

The overwhelming majority of supervisors do not think that the existence of SRCP in any way makes CCPED administration more difficult. Several coordinators described the program as "complementary". One coordinator noted, "There are no difficulties. CCPED serves care recipients primarily and SRCP serves caregivers." Another coordinator offered, "The SRCP is a godsend to CCPED. For example, the house of a CCPED client burnt down. The family had a place to go, but there was no room for grandpa (care recipient). SRCP provided emergency respite placement for him in a nursing home." In light of the home health aide shortage, the impact of which was felt by almost every coordinator interviewed, coordinators were asked about competition for aides between the two programs. Most supervisors do not feel competition for service providers from the SRCP, as SRCP provides a limited amount of service compared to CCPED. Finally, most supervisors do not see the room or need for collaboration between the two programs beyond what most already do in providing complementary services, sharing resources, and preventing the duplication of services.

Program Implications

Timing of Entry to Respite

As with SRCP, a substantial number of supervisors, representing both the elderly and special child service groups, feel that clients seek CCPED services during the late stages of the care recipient's condition.[7] "Clients tend to apply for CCPED during the late stages of their disease. We see this especially among our clients with dementia," reported one supervisor. She added, "This makes it very difficult to get clients the appropriate services as quickly as they need them." Several supervisors often see clients seeking help while they are experiencing a crisis, as opposed to planning ahead to avoid unanticipated setbacks (e.g., illness of the primary caregiver or a sudden change in the care recipients' medical condition). One supervisor of special child health CCPED explained that there are

a number of issues that discourage families with young disabled children from approaching CCPED for help. For example, families can be wary about allowing strangers into their home (e.g. home health aide) to care for their child, let alone allowing an aide to spend several days providing in-home respite. Another supervisor noted certain social obstacles on the part of the families when considering CCPED. "A visit to the county welfare office can be a humbling experience for our young parents. This may deter them from accessing our services. They are not used to this."

Several coordinators, on the other hand, described a client population that enters the program during the middle stages of disease. This is especially seen with care recipients who undergo a sudden change in their disease or disability. Perhaps the caregivers and family members of care recipients who experience sudden traumatic medical events are more predisposed to seek respite care earlier, as they witness a rapid deterioration of the care recipient's condition.

Perceived Benefits of the CCPED Program

Perceived Benefits for the Care Recipients

The most commonly mentioned benefits of CCPED to the care recipients were preserving the client's sense of independence through continued residence at home and the financial relief associated with receiving services and prescription drugs without having to worry about payment. Another benefit noted by a few supervisors is the potential prevention of neglect and abuse through the early provision of in-home services. In addition, a couple of supervisors feel that the case management component of the CCPED program and the associated client advocacy is a huge benefit to the care recipients. Many supervisors perceive benefits stemming from the flexibility and accessibility of care managers in their response to the individual needs of their clients.

Perceived Benefits for the Caregivers

A substantial number of supervisors agreed that the services offered through the CCPED program effectively provide relief to the caregivers. "The program provides them (caregivers) with a peace of mind in knowing that their loved ones are receiving good care," noted one supervisor. Another supervisor mentioned that the program allows many caregivers to go to work. She explained, "A caregiver without an income would be financially burdened tremendously without CCPED."

Perceived Benefits for the Special Child Health Population

Perceived benefits for children in CCPED included coverage of services that might not be paid for by insurance plans (e.g. therapy), the provision of consistent care for the child, relief of the

parents, and an increase in the child's social network. "Mom is not as frazzled and she can focus on her child's needs with the extra help," commented one supervisor. Another supervisor believes that the case management and services save marriages.

Perceived Benefits for Case management Agencies

Six supervisors feel that the revenue drawn from the $95/month case management fee per client is a major benefit to the host agency, but eleven of the supervisors volunteered that this fee only partially offsets the cost of administering the program. Despite the loss taken by the agency, many of them feel that the agency is still proud to maintain this program for one or more of the following reasons: The CCPED mission is consistent with the NJEASE initiative (which is implemented by many of the host agencies), administering CCPED provides for a budget to have more care managers on staff, or the program enhances the agency's reputation within the community.

Satisfaction Surveys

Only two care management sites reported ever using satisfaction surveys to gain feedback on the program's administration. One of the sites utilizes the sponsor agency's general satisfaction survey; hence the questions are not specific to the CCPED program. The other site had used a survey designed specifically for CCPED, but has discontinued its use in recent years due to the lack of personnel to process the surveys.

Part III: Program Clients and Services: Analysis of the Administrative Database

Program Clients

Six hundred and fifty-three CCPED clients used respite services from 1993 to 1999. Table 1a shows the characteristics of these clients. As the table shows, three-quarters of these clients were female, and most had a primary diagnosis of a physical disease or disability. The vast majority were elderly, and six out of ten were over 75. Clients were close to being evenly split between the poor and near-poor. As shown in Table 1b, in half of the cases, the primary caregiver was a child of the client, and in another 22.2%, it was a spouse. Interestingly, given that respite is usually viewed as a form of caregiver relief, 7.7% of the clients who used this service were listed as having no caregiver.

Table 1a: Client Characteristics

Characteristics	Number	Percent
Gender (n=653)		
Male	163	25
Female	490	75
Diagnosis (n=652)		
Mental	114	17.5
Injury	11	1.7
Other Physical Condition	514	78.8
Other Unspecified Condition	12	1.8
No Condition	1	.2
Age at Entry into Program (n=653)		
0-18	3	0.5
19-39	17	2.6
40-64	83	12.7
65-74	144	22
75-84	226	34.6
85+	180	27.6
Monthly Income (n=653)		
$0-749	347	53.1
$750+	306	46.9

Table 1b: Relationship of Caregiver to Client

Relationship	Percent (n=653)
Spouse	22.2%
Child	52.2
Sibling	3.5
Parent	3.1
Other relative	8.0
Friend	2.5
Neighbor	0.2
None	7.7
Assisted Living Resident	0.3
Comprehensive Personal Care Home	0.5
Alternate Family Care	0

The profile of the CCPED respite users conforms well to what we would expect based on our general knowledge of disability and caregiving, and is largely similar to that of the clients of the New Jersey Statewide Respite Care Program (Silberberg and Caruso, 2001). SRCP clients were more likely to have a recorded diagnosis of dementia than CCPED clients were to have a diagnosis of mental condition, but this may be in part a function of the fact that the SRCP database records two diagnoses. SRCP, of course, does not include children under 18, but this is a small group even among CCPED respite users. CCPED clients are also somewhat more likely to be poor as measured by income than are SRCP clients; this makes sense given the SRCP's higher asset limitation and the likelihood of an association between income and assets.

Changes in Clients

As seen in Table 2a, the client base does show changes over the years. Most importantly, from 1993 to 1999, there was an increase in the number of respite users. This is not surprising, given that there was an expansion of program slots in 1993 and again in 1998. Over those seven years, there was also an increase in the percentage of clients who were male (although the clientele continued to be primarily female), and the percentage of clients below the poverty level declined from 64.1% in 1993 to 44.8% in 1999. It may be that expansion of the program led to greater penetration into the male and near-poor populations, the less traditional participants in the program.

Table 2a: Client Characteristics by Year

	Year						
	1993 (n=64)	1994 (n=96)	1995 (n=103)	1996 (n=156)	1997 (n=189)	1998 (n=218)	1999 (n=203)
Gender							
Male	15.6%	18.8%	27.2%	21.2%	27.5%	30.3%	26.6%
Female	84.4	81.3	72.8	78.8	72.5	69.7	73.4
Diagnosis (DIAG)							
Mental Condition	17.2	24.0	13.6	13.5	14.3	14.7	17.7
Injury	3.1	4.2	2.9	.6	1.1	1.8	.5
Other Physical Condition	76.5	70.8	82.5	83.4	83.6	80.7	80.3
Other Unspecified Condition	1.6	0	0	1.9	.5	2.3	1.5
No Condition	1.6	1.0	1.0	.6	.5	.5	0
Age at Entry into Program							
0-18	0.0	1.0	0.0	0.0	0.0	0.0	1.0
19-39	4.7	6.3	3.9	1.9	1.1	3.2	2.4
40-64	10.9	14.6	15.5	18.6	11.6	9.6	13.3
65-74	23.5	27.1	26.2	21.8	21.7	25.7	19.8
75-84	42.4	33.3	34.0	31.4	37.0	30.3	35.9
85+	18.7	17.7	20.4	26.3	28.6	31.2	27.6
Monthly Income							
$0-749	64.1	59.4	58.3	54.5	51.9	44.5	44.8
$750+	35.9	40.6	41.7	45.5	48.1	55.5	55.2

Table 2b: Relationship of Caregiver to Client by Year

	Year						
Relationship	**1993 (n=64)**	**1994 (n=96)**	**1995 (n=103)**	**1996 (n=156)**	**1997 (n=189)**	**1998 (n=218)**	**1999 (n=203)**
Spouse	15.6%	20.8%	17.5%	20.5%	22.2%	18.3%	17.7%
Child	57.8	59.4	60.2	55.8	58.2	56.9	56.2
Sibling	9.4	5.2	5.8	3.2	3.2	3.7	2.0
Other relative	7.8	2.1	6.8	8.3	7.4	7.8	9.9
Friend	0	1.0	1.0	1.3	1.6	3.2	3.0
Neighbor	0	0	0	.6	0	0	0
Parent	4.7	7.3	2.9	3.8	1.6	2.8	3.9
None	4.7	4.2	1.0	.6	4.8	6.9	6.4
Assisted Living Resident	0	0	0	0	0	0	.5
Comprehensive Personal Care Home	0	0	0	0	1.1	.5	.5
Alternate Family Care	0	0	0	0	0	0	0

Variations by County

County-level data are provided in Tables 3a through 3e. Given the small sample size, it is not feasible to establish patterns by county, and data are provided only for descriptive purposes. It is assumed that they will be primarily of interest to staff.

Table 3a:Client Gender by County

	Gender	
County	**Male**	**Female**
Atlantic (n=24)	41.7%	58.3%
Bergen (n=51)	25.5	74.5
Burlington (n=49)	30.6	69.4
Camden (n=23)	17.4	82.6
Cape May (n=1)	0.0	100.0
Cumberland (n=7)	14.3	85.7
Essex (n=96)	20.8	79.2
Gloucester (n=10)	20.0	80.0
Hudson (n=9)	23.7	76.3
Hunterdon (n=0)	n/a	
Mercer (n=33)	36.4	63.6
Middlesex (n=50)	16.0	84.0
Monmouth (n=71)	25.4	74.6
Morris (n=33)	12.1	87.9
Ocean (n=78)	29.5	70.5
Passaic (n=12)	25.0	75.0
Salem (n=2)	0.0	100.0
Somerset (n=10)	20.0	80.0
Sussex (n=8)	0.0	100.0
Union (n=56)	33.9	66.1
Warren (n=1)	0.0	100.0

Table 3b: Client Diagnosis by County

	Diagnosis				
County	Mental	Injury	Other Physical Condition	Other Unspecified Condition	No Condition
Atlantic (n=24)	12.5%	0%	87.5%	0%	0%
Bergen (n=51)	29.4	2.0	68.6	0	0
Burlington (n=49)	16.3	0	81.7	0	2.0
Camden (n=23)	21.7	0	78.3	0	0
Cape May (n=1)	0.0	0	100.0	0	0
Cumberland (n=7)	28.6	0	71.4	0	0
Essex (n=96)	7.3	2.1	85.4	5.2	0
Gloucester (n=10)	20.0	10.0	70.0	0	0
Hudson (n=9)	31.6	0	68.4	0	0
Hunterdon (n=0)			n/a		
Mercer (n=33)	3.0	3.0	87.9	6.1	0
Middlesex (n=50)	22.0	2.0	76.0	0	0
Monmouth (n=71)	12.9	1.4	85.7	0	0
Morris (n=33)	21.2	6.1	72.7	0	0
Ocean (n=78)	24.4	2.6	70.4	2.6	0
Passaic (n=12)	8.3	0	0	0	0
Salem (n=2) (n=2)	100.0	0	0	0	0
Somerset (n=10)	10.0	0	90.0	0	0
Sussex (n=8)	12.5	0	75.0	12.5	0
Union (n=56)	12.5	0	83.9	3.6	0
Warren (n=1) (n=1)	100.0	0	0	0	0

Table 3c: Client Age at Entry by County

	Client Age					
County	**0-18**	**19-39**	**40-64**	**65-74**	**75-84**	**85+**
Atlantic (n=24)	0.0%	4.2%	12.6%	8.4%	54.6%	21.0%
Bergen (n=51)	0.0	0.0	8.0	18.0	26.0	50.0
Burlington (n=49)	2.0	2.0	10.0	22.0	32.0	30.0
Camden (n=23)	0.0	4.3	13.1	17.4	30.4	34.8
Cape May (n=1)	0.0	0.0	0.0	0.0	0.0	100.0
Cumberland (n=7)	0.0	0.0	0.0	28.6	71.5	0.0
Essex (n=96)	0.0	3.0	19.0	22.0	31.1	21.1
Gloucester (n=10)	0.0	0.0	0.0	40.0	20.0	40.0
Hudson (n=9)	0.0	0.0	5.2	36.4	39	18.2
Hunterdon (n=0)	n/a					
Mercer (n=33)	0.0	0.0	21.0	27.0	18.0	33.0
Middlesex (n=50)	0.0	2.0	12.0	28.0	38.0	20.0
Monmouth (n=71)	0.0	4.2	9.8	19.6	43.4	22.4
Morris (n=33)	3.0	9.0	12.0	6.0	24.0	45.0
Ocean (n=78)	0.0	2.6	10.4	20.8	37.7	29.9
Passaic (n=12)	8.3	0.0	0.0	49.9	16.6	24.9
Salem (n=2)	0.0	0.0	0.0	50.0	0.0	50.0
Somerset (n=10)	0.0	0.0	20.0	30.0	30.0	20.0
Sussex (n=8)	0.0	0.0	25.0	25.0	37.5	12.5
Union (n=56)	0.0	3.6	19.8	16.2	39.6	21.6
Warren (n=1)	0.0	0.0	0.0	0.0	100.0	0.0

Table 3d: Client Income by County

Monthly Income		
County	**Income $0-749**	**Income $750+**
Atlantic (n=24)	95.8	4.2
Bergen (n=51)	33.3	66.7
Burlington (n=49)	36.7	63.3
Camden (n=23)	43.5	56.5
Cape May (n=1)	100.0	0.0
Cumberland (n=7)	42.9	57.1
Essex (n=96)	56.2	43.8
Gloucester (n=10)	40.0	60.0
Hudson (n=9)	47.4	52.6
Hunterdon (n=0)	n/a	
Mercer (n=33)	33.3	66.7
Middlesex (n=50)	66.0	44.0
Monmouth (n=71)	67.6	32.4
Morris (n=33)	57.6	42.4
Ocean (n=78)	47.4	52.6
Passaic (n=12)	41.7	58.3
Salem (n=2) (n=2)	0.0	100.0
Somerset (n=10)	50.0	50.0
Sussex (n=8)	25.0	75.0
Union (n=56)	67.9	32.1
Warren (n=1)	100.0	0.0

Table 3e: Caregiver Relationship by County

	Relationship					
County	**Spouse**	**Child**	**Other Relative**	**Friend**	**None**	**Other**
Atlantic (n=24)	20.8%	29.2%	20.9%	0.0%	29.2%	0.0%
Bergen (n=51)	13.7	80.4	2.0	0.0	3.9	0.0
Burlington (n=49)	18.4	57.1	18.3	0.0	4.1	2.0
Camden (n=23)	26.1	65.2	4.3	0.0	4.3	0.0
Cape May (n=1)	0.0	0.0	100.0	0.0	0.0	0.0
Cumberland (n=7)	28.6	28.6	0.0	28.6	14.3	0.0
Essex (n=96)	16.7	43.8	28.1	6.2	5.2	0.0
Gloucester (n=10)	20.0	40.0	20.0	0.0	20.0	0.0
Hudson (n=9)	18.4	60.5	0.0	2.6	18.4	0.0
Hunterdon (n=0)	n/a					
Mercer (n=33)	27.3	48.5	15.2	3.0	6.1	0.0
Middlesex (n=50)	28.0	58.0	2.0	0.0	8.0	4.0
Monmouth (n=71)	25.4	45.1	23.9	2.8	1.4	1.4
Morris (n=33)	15.2	63.6	12.1	3.0	6.1	0.0
Ocean (n=78)	33.3	39.7	14.1	0.0	11.5	1.3
Passaic (n=12)	25.0	50.0	8.3	8.3	8.3	0.0
Salem (n=2)	50.0	50.0	0.0	0.0	0.0	0.0
Somerset (n=10)	20.0	70.0	10.0	0.0	0.0	0.0
Sussex (n=8)	0.0	75.0	0.0	0.0	25.0	0.0
Union (n=56)	23.2	51.8	16.1	5.4	3.6	0.0
Warren (n=1)	0.0	100.0	0.0	0.0	0.0	0.0

Income and Age as Compared to the Low-Income Adult Disabled Population

Census data provide us with a rough estimate of the low-income adult disabled population in each county and in the state overall. They also provide information on the percentage of this group that is elderly and non-elderly and the percentage that is poor and near-poor. Using these data as a point of comparison for the program data is complicated by the fact that the census data only address those 16 and over, by the rough nature of the estimate, and by the small number of

CCPED respite users when broken down by county. However, the census data do provide a general picture of the target population. As with the SRCP, we see an overall trend for CCPED respite users statewide and across the counties to be as poor as or poorer than the low-income disabled. This is a favorable finding, since the poor are financially needier than the near-poor, and are likely to be as needy or needier than the near-poor in terms of their disabilities. Also as with the SRCP, the CCPED respite users are older overall than the low-income adult disabled population, as defined through the census; again, this is true throughout the state.

Reasons for Entry Into and Exit from CCPED

The CCPED database records a reason for application to the program, using fourteen fixed codes. Among respite users, the most common reason for applying – pertaining to one-third of the population – was "recent deterioration of medical condition." [See Table 4a.] Other common reasons included "primary caregiver needs relief" (22.4%), "increased dependency in ADL and IADL" (15.2%) and "other funding sources depleted" (14.4%). Changes in physical/mental or financial condition then most commonly precipitated clients' entry into the program. However, caregiver needs, including relief and employment (another 6.4%), were central in almost three out of ten cases. Few individuals were coded as entering the program because of discharge from a hospital, nursing facility, or rehabilitation program, and none were coded as applying due to a need for medication management or housing.

Table 4a: Reason for Application to Program

Reason	Percent
Recent deterioration of medical condition	35.6%
Loss of primary caregiver	.8
Accident or injury	.9
Other funding sources depleted	14.4
Primary caregiver needs relief	22.4
Increased dependency in ADL and IADL	15.2
Caregiver employed outside the home	6.4
Discharged from hospital	.2
Discharged from nursing facility (NF)	1.5
Return from out-of-state rehabilitation center or NF	0
Conversion from private pay, same placement	1.2
Needs medication management	0
Needs appropriate housing	0
Other	1.2

Forty fixed codes are used in the CCPED database to record the reason for a client's termination. Nonetheless, two codes together accounted for three-quarters of the terminations – entry into nursing home, comprehensive, or residential health care facility (54.0%) and client death (29.2%). Another 8.4% of terminations were due to the client being in the hospital for more than 30 days. Reflecting the frailty of the clients, termination, then, usually results because institutional care becomes necessary. It is much less likely to be the result of transfer to another program, and is rarely due to client dissatisfaction or problems with service acquisition. Compared to the SRCP, the CCPED clients are equally likely to terminate due to death but twice as likely to terminate due to institutionalization and much less likely to terminate due to being put on another program. At least in part, this probably reflects the fact that SRCP is a much more limited program, and clients are therefore likely to move to other programs like CCPED when they are able.

Table 4b: Reason for Termination[i]

Reason	Percent
Entry into nursing home, comprehensive care facility, or rehabilitative care facility	54.0%
Died	29.2
Moved out of state	2.8
No services available	.9
Not satisfied with program	.2
In hospital more than thirty days	8.4
Financially ineligible	1.2
Client withdrew – no reason	1.9
Transferred to NJ Care	4.7
Transferred from CCPED to other program	.7
Transferred to Personal Assistance Service	.2

[8] A number of possible termination codes had no terminations ascribed to them: transfer to CCPED, transfer to Model Waiver I, transfer to Model Waiver II, transfer to Model Waiver III, cost-share, loss of primary caregiver, medically ineligible, cost of services exceeds cap, eligible for SSI, eligible for medically needy program, transferred to ACCAP, HSP number changed from disabled to old age, went from SSI to SSD, services no longer required, change in HSP number, HIV+ child over 5 years old, SSI or SSD disability denied, unable to make contact with client, client incarcerated, transferred to HCEP, transferred from ACCAP to ABC, transferred to DDD, CCW, eligible for Title 4-E, transferred from CCPED to TBI, transferred from TBI to CCPED, transferred to hospice, transferred to EPSDT, and transferred from ABC to ACCAP.

No striking changes over time are seen in reasons for applications or reasons for termination.

Service Use

Overall, the likelihood of a particular service type being used appears to vary positively with the service intensity. At one end of the spectrum, clients used a total of 2370 units of nursing home respite, and at the other end, 183 units of eight-hour night respite. Forty-one percent of respite users had used no in-home respite at all. Of the in-home respite, twelve-to-twenty-four-hour care is most common, and then eight-to-twelve-hour night respite.

This service use pattern is in marked contrast to that of the SRCP, in which homemaker/home health aide respite was by far the most frequently used. This contrast makes sense, since in the CCPED program, clients can receive non-respite home-based services, and respite is generally conceived of as a sporadic event, usually occurring due to caregiver illness, travel, or some other extended interruption.

Clients were most likely to have used only a few units of any respite service over the course of their time in the program, a number had used several units, and some had used a great deal more; the maximum was 52 units of eight-to-twelve-hour day respite.

Service Use and Diagnosis

We wanted to know whether clients who were coded as having a "mental" condition used services differently than clients with diagnoses of physical illness or injury or other diagnoses. As in our study of the SRCP, we found some interesting and logical differences. These are shown in Table 5a. While there was no difference in use of eight-hour services, patients with a mental diagnosis were significantly less likely to have used in-home respite services for the longer periods. Conversely, they were more likely to have used nursing facility care.

Table 5a: Service Use by Diagnosis

Service Type	Percent of Respite-Using Clients Using Specific Service Type		Sig.
	Clients with a Mental Diagnosis	Clients with Other Diagnoses	
8-hour day	9.6%	12.8%	
8-hour night	3.5	6.3	
12-hour day	12.3	22.1	*
12-hour night	15.8	26.2	*
12-24-hour	25.4	36.7	*
Nursing facility	60.5	40.4	*

*Significant at the .05 level.

Service Clusters

As shown in Table 5b, clients were mostly likely to have used one type of respite service; the average number was 1.42.

Table 5b: Numbers of Different Respite Services Used

	Percent of Clients Using Number of Services	
Number of Different Respite Services Used	Number (n= 653)	Percentage
1	466	71.4
2	122	18.7
3	50	7.7
4	12	1.8
5	2	.3
6	1	.2

Two patterns presented themselves in the ways that services clustered. Daytime and nighttime use of similar durations tended to be associated, including eight-hour day care with eight-hour night care, and eight-to-twelve hour day care with eight-to-twelve-hour night care. Using each of the forms of in-home care was negatively associated with using nursing home care.

Duration in Program

Time in the CCPED is surprisingly long. For those respite users who had already terminated, median duration was 1027 days, i.e. 2.8 years. Ten percent of those who had terminated were in the program between 7.5 and 12.1 years.

Respite Expenditures

Respite accounts for a small part of program expenditures. The average respite user had accessed respite services costing $2856.41 over their time in the program. The median expenditure for respite was only $960. However, ten percent of respite users had used services totaling over $5,000. Both because of its per unit cost and its frequent use, nursing home respite was of course a major factor in total expenses, accounting for 71.3% of the total.

Part IV: Conclusion

Respite is one of eight home and community-based services offered through CCPED. As such, it takes on a different conception than in a stand-alone respite program like the SRCP. In the context of the stand-alone program, all services provided are understood to be respite, and respite is most likely to be used on a regular basis, as a form of periodic caregiver relief. The waiver program, however, is designed to provide a wide range and large volume of services. Those services perceived by staff to be most important for clients are homemaker/home health aide, day care, transportation, and the pharmacy benefit. In that context, respite represents a more limited set of options than it does for SRCP, and has generally come to mean something outside of the standard services, usually used in case of a caregiver emergency, vacation, illness, or another anomalous event. Not surprisingly, then, institutional respite is dominant in CCPED, as opposed to home-based in SRCP, and clients are likely to have used only a few units of respite during their time in the program. Nonetheless, 653 clients had used respite in the seven-year period studied here, suggesting that it is an important stop-gap service.

The broader range and much larger quantity of services provided by CCPED are also reflected in the different termination patterns of SRCP and CCPED. CCPED terminations are much more likely to be due to institutionalization and much less likely to be due to transfer to another program.

Conceptions of SRCP and CCPED are different in two additional related ways. First, while the programs share the goals of relieving caregivers and preventing institutionalization, preventing institutionalization is primary for CCPED and caregiver relief is primary for SRCP. Second, the care recipient is considered the primary client in CCPED, whereas care recipients and caregivers are equally clients for SRCP. County supervisors understand the CCPED program's goals, and differences between CCPED and SRCP respondents in program conception conform to the actual differences in the two programs' design and priorities just described. In pursuing program goals, CCPED respondents – like the SRCP staff – evidence flexibility and a client service orientation.

Implementation of the CCPED program shows a number of other strengths as well. Poorer segments of the target population are well-represented among program clients. Both county supervisors and DHSS staff are happy with intraprogram relationships, citing open lines of communication, timely responses to concerns, and strong state support of the counties.

Some challenges for CCPED also emerged in the interviews. Most importantly, perhaps, several CCPED respondents suggested that the program's emphasis on preventing institutionalization and respect for consumer autonomy might be leading them to provide services to people at home who are so debilitated as to be unsafe in the home setting. They argued that a change in emphasis was needed, or a change in the assessment process.

Another concern for program staff – one familiar from the SRCP study – was the difficulty of finding service providers. In particular, home health aides are scarce and it can be difficult to find nursing homes that will take clients for short- term stays. Special child health supervisors also noted a need for more specialized services for their clients.

A bureaucratic challenge for many CCPED care management supervisors is the division of responsibilities between the care management site, the LTCFO, and the BSS/CWA. This division of responsibility can create delays and communication failures. In many cases, it means that care managers have no contact with clients once they are deemed financially ineligible for CCPED, thus eliminating the opportunity to refer clients to other programs, including the SRCP.

One way in which counties differed was in whether they maintained regular oversight of vendors. Supervisors could benefit from clarification of their roles and responsibilities in this area.

Special Child Health agencies face unique challenges in terms of the special needs of their clientele. As noted above, they perceive an inadequate supply of providers with the specialized services they need. They also find the regional meetings with DHSS to be of less help to them than to the agencies who serve senior populations.

Supervisors perceive the CCPED program to have great benefits for clients. As with the SRCP, clients who were diagnosed as having a mental condition used services differently than clients with physical diagnoses. Also, as with SRCP, interviewees perceived clients to be coming into the program at late stages. Median duration in the program is relatively long compared to the SRCP, suggesting that late entry may not be as large a problem for CCPED. However, supervisors feel that the program could be of even greater benefit if clients entered the program earlier.

Endnotes

[1] A program for the developmentally disabled that includes respite services has not been studied for this project.

[2] Eighteen supervisors, who represent 19 of the agencies administering care through CCPED, were interviewed. One supervisor administers the program for two counties through the same the service agency.

[3] Stephen Crystal, Edmund Dejowski, and Pearl Beck, "Evaluation of the New Jersey Respite Care Pilot Project," Report to the New Jersey Department of Human Services, 1992.

[4] NJEASE is New Jersey's new strategy of providing information and referrals to the full gamut of senior services through personnel at one phone number.

[5] 1997 U.S. Census model-based estimates

[6] This change was first implemented in a few counties in 1998 and completed in 1999.

[7] The supervisors base their impressions of their care recipient's medical conditions at the time of entry on a number of sources including assessment forms completed by nurses from the LTCFO, observations made by care managers at the care recipient's home, and information provided by the family.