THE CENTER FOR STATE HEALTH POLICY

New Jersey's Statewide Respite Care Program: A Study of Program Design, Implementation, Clients, and Services

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NEW JERSEY'S STATEWIDE RESPITE CARE PROGRAM: A STUDY OF PROGRAM DESIGN, IMPLEMENTATION, CLIENTS, AND SERVICES

EXECUTIVE SUMMARY

INTRODUCTION

From January 2000 to January 2001, Rutgers' Center for State Health Policy conducted a study of the New Jersey Statewide Respite Care Program (SRCP). The research was commissioned by the national Alzheimer's Association, and carried out in cooperation with the New Jersey Department of Health and Senior Services (DHSS) and the Greater New Jersey Chapter of the Alzheimer's Association. The impetus for the study was in large part the program's status as a model for caregiver support. The study aims to provide useful information on program operations both for those running the program and those seeking to replicate this program or some of its elements in other contexts.

METHODS

The study employed two data sources. The first was interviews with program staff – both staff at DHSS and county coordinators at the local sponsor agencies, which contract with the state to administer the program. The second data source was administrative data on clients and services from 1993 to 1999, primarily addressing the 7965 care recipients in this time period and their associated caregivers. These quantitative and qualitative data were used to describe and analyze: program design and implementation, important program changes and key contextual factors affecting program operations, the client profile, and service use patterns.

KEY FINDINGS

- **Mission and Approach:** Staff show a strong understanding of program goals and a clear commitment to both caregiver and care recipient clients, as reflected in a flexible, creative, client-driven approach to program implementation and enhancement. Coordinators play an important case management role for their clients, lending support to the idea of creating universal eligibility with cost-share going up to 100%. Some specific questions for future program direction are raised by care recipients who need more than respite, the impact of new state home care programs, and the program's current emphasis on the elderly.
- **Participation:** All counties are effectively bringing in clients, and the poorer segments of the target population are impressively well-represented among care recipients. However, the younger disabled are underrepresented. In 1998, there was an attempt to increase participation by wife caregivers by basing financial eligibility determination on the income of a married couple rather than that of the care recipient alone. This change appears not to have had the desired effect, perhaps because the $40,000 asset limitation for individuals was extended to couples.

- **Budget:** As with most government programs, staff perceive limitations on their work resulting from budget restrictions. In particular, staff see the budget as limiting per client expenditures (finding the current $3,000 cap restrictive), needed staffing, outreach activity, and their ability to serve all those who meet the eligibility requirements. The wait-list is not a good measure of unmet need because outreach is limited when the program is full. However, the administrative data lend support to some of the staff contentions.
- **Statewide Implementation**: Program operations and internal relations receive high marks from both state and sponsor agency staff, despite a common perception that the program could benefit from more staff overall. Communication, organization, commitment, and oversight are keys to this perceived effectiveness.
- **Local Implementation:** Our data suggest a number of local conditions that affect program implementation: the local home and community-based care market, the availability of free services, population density, county size, and county income distribution. However, our data also suggest that some aspects of local implementation are less a function of different local circumstances than of sponsor agency characteristics, especially the purpose and clientele of the larger agency. Because of the flexibility they are afforded, the sponsors function as "laboratories" for program implementation. As staff recognize, this experimentation needs to be balanced against the need for consistency and best-practice learning, which the program should continue to encourage.
- **Program Flexibility and Convenience:** Respondents cite a number of dimensions of program flexibility and convenience as strengths. These include the ease of the application process and eligibility determination, the diversity of services, flexibility in deviation from service plans, the ease of obtaining cost cap extensions, and discretionary use of cost-share funds.
- **Service Use and Diversity:** The data strongly support the importance of the program's service diversity, particularly in meeting the needs of a population with different disabilities and different levels of need.
- **Clients with Alzheimer's Disease/Senile Dementia:** Clients with Alzheimer's disease/senile dementia differed from other clients in duration in program, reasons for termination, and types of services used. Clients with AD/SD were far less reliant on home care than the client population overall and far more reliant on day care
- **Market Restrictions:** Like most community-based long-term care programs, SRCP faces some challenges stemming from inadequacies in the private market, particularly in certain communities. The current home health aide shortage in particular is making the coordinators' jobs more difficult, and there has been a dip in the percentage of clients using home health aides in counties in which the sponsor is not a home health agency.
- **Benefits to Clients**: Nationwide, late entry into respite programs is a major concern, and this appears to be a reality for SRCP as well. Respondents described several important benefits to clients when they do come to the program. Two perceived benefits mirror the program's goals: caregiver relief and delayed institutionalization. The limited satisfaction survey data available lend support to these perceptions, and to staff perceptions that the quality of the care being provided is good. The flexibility for which SRCP is known is seen as an important element in achieving client benefits.

NEW JERSEY'S STATEWIDE RESPITE CARE PROGRAM: A STUDY OF PROGRAM DESIGN, IMPLEMENTATION, CLIENTS, AND SERVICES

PART I

INTRODUCTION

OVERVIEW

This report presents the findings of a study of the New Jersey Statewide Respite Care Program (SRCP) conducted from January 2000 to January 2001 by the Center for State Health Policy at Rutgers. This study was commissioned by the national Alzheimer's Association, and carried out in cooperation with the New Jersey Department of Health and Senior Services (DHSS) and the Greater New Jersey Chapter of the Alzheimer's Association.

The impetus to conduct this study is the status of the SRCP as a model for caregiver support.[1] Implemented in April of 1988, the program has provided respite services for over 10,000 care recipients.[2] A hallmark of the program is the wide range of respite services it provides, including a variety of in-home, community-based, and institutional options.

The study utilized two types of data: interviews with program staff from the Department of Health and county coordinators, and analysis of the program's computerized administrative data set for the years 1993 to 1999.[3] This data was utilized to describe the program's design and implementation, important program changes, contextual factors affecting program operations, perceived strengths and weaknesses of the program, the client profile, and service use patterns.

BACKGROUND

The SRCP has been operational since April of 1988. The program has historically been financed by state Casino Revenue Funds, with a supplement from a client cost-share based on a sliding scale. Recently, additional funds were added from the tobacco settlement, bringing the current annual program budget to $6.75 million. Originally located in the Department of Human Services, the program moved to the new Department of Health and Senior Services (DHSS) with the consolidation of programs for the elderly in 1996. It is located in the department's Division of Senior Affairs, Office of Community Programs.

The SRCP has two primary goals: to provide relief and support to unpaid caregivers of frail elderly or disabled adults, and to delay institutional placements. The care recipients therefore are functionally impaired adult care recipients (18 or over) and their unpaid routine caregivers. Care recipients must meet financial eligibility requirements of $1,590 or less per month ($3,180 for married couples) and liquid resources of less than $40,000. Individuals who are eligible for respite care or related services under the Community Care Program for the Elderly and Disabled (CCPED — a Medicaid waiver program) may receive SRCP services if they have needs that cannot be met through CCPED; this is determined by DHSS on a case-by-case basis. While CCPED has the same income threshold as SRCP, it has a much lower asset limitation — $2,000 for individuals and $3,000 for couples.

The SRCP is administered locally by county coordinators working for sponsor agencies that have contracted with the state for this purpose. The major types of respite services provided through the program are companions (paid and volunteer), homemaker/home health aides (hourly, 12-hour, or 24-hour), private duty nursing, medical or social adult day health services, camperships (a camp setting for the younger disabled providing recreational and social opportunities)[4], and temporary care in licensed medical facilities (nursing homes, hospitals[5], intermediate care facilities, and residential health care facilities). However, not every service must be offered in every county, and counties may also offer services that are not part of the standard list. The standard service expenditure cap is $3,000, although clients may be assigned lower caps upon entry into the program and may appeal for an allowance over the $3,000 limit. Some reimbursement rates are tied to the Medicaid payment rate. Using average service rates, the cost cap allows for four hours of home health aide care, two sessions of social adult day care, or one session of medical day care per week.

The SRCP was studied in 1992. That study, headed by Steven Crystal of the Rutgers Institute for Health, Health Care Policy, and Aging Research, used three sources of data: interviews and surveys of coordinators, a survey of service vendors, and interviews with caregivers and care recipients. The study addressed program design implementation, the client profile, and perceived strengths, weaknesses, and impact[6].

Given the number of years since the last evaluation and the continued importance of the SRCP as a model for caregiver support, the Alzheimer's Assocation and DHSS felt it appropriate to commission a new study of the program that would provide information both for those running the New Jersey program and those seeking to replicate this program or some of its elements in other contexts. They also recognized a significant untapped research opportunity in the computerized administrative data system used by the program from 1992 through 1999.[7]

The Center for State Health Policy was commissioned to carry out this study with the assistance of a project Advisory Committee, comprised of representatives of the Alzheimer's and Related Disorders Association, the New Jersey Department of Health and Senior Services, and the Center for State Health Policy.

STUDY QUESTIONS AND METHODS

For the purposes of assisting those running the New Jersey program and those seeking to promote effective caregiver support elsewhere, 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—overall and in specific counties?
4. What are perceived as, and what have been, important changes in program design?
5. What are perceived as, and what are, important aspects of the policy, market, and demographic context for program operations?
6. Who is served by this program, including age, gender, income, caregiver relationship, and diagnosis?

7. What kinds of services are utilized, at what intensity levels, and by what kinds of clients? How are services bundled?
8. What data is being collected about client satisfaction?

Two methods were used to answer these questions. First, DHSS staff and coordinator 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 Crystal's 1992 study, and the input of the Advisory Committee. (See Appendix I, page 47 for instrument.) Interviews were conducted with two program administrators from NJDHSS and representatives of all the county sponsor agencies, in virtually all cases the county coordinator.

Second, we compiled and analyzed the computerized administrative data files of the program for 1993 to 1999. These files contain the following data elements:

- County of service
- Care recipient characteristics: date of birth, gender, and up to two diagnoses. Income categories can also be determined from the levels of cost-share assigned to program participants.[8]
- Caregiver relationship to care recipient.
- Status in the program and related dates: on the waiting list, using emergency services, accepted into the program, active, suspended for reaching cost cap, and terminated. Nine classifications are provided for reason for termination.
- Conditions of participation: Assigned cost-share and cost cap.
- Utilization: Type and amount of services utilized each month, as well as reason for service use.
- Expenditures: Per unit cost for each episode of care.

Our analysis is primarily of individuals in the data set whom we have defined as program participants. Participants include individuals who were either accepted into the program or used emergency services or both.[9] These selection criteria resulted in a data base of 7,965 program participants in the years 1993-1999.

The other group of individuals whom we were able to study from the administrative database was wait-listed consumers, some of whom—but not all—later became program participants. A section of the report is dedicated to analysis of this group of individuals.[10]

In our analysis, qualitative interview data and quantitative administrative data were analyzed together to assess the significance of program changes and context. Interviews were used, with the input of the Advisory Committee, to identify key program and contextual changes, as well as key county differences, and to generate hypotheses about their potential impact on the client profile and utilization patterns represented in the administrative data set.

The perspective missing from this report for the most part is that of the clients, as resources did not permit client interviews. However, we report on the limited client satisfaction survey data that is available.

REPORT OUTLINE

The rest of the report is presented in three sections. Part II addresses the findings of the staff interviews, focusing on program implementation and perceived implications for clients. Part III addresses the analysis of the administrative database, including client profile, service patterns, and assessment of the impact of key context and policy changes identified in the interview data. Part IV offers some summary remarks.

PART II

PROGRAM IMPLEMENTATION AND OUTCOMES: PERSPECTIVES OF THE PROGRAM STAFF

ADMINISTRATIVE STRUCTURE

The Statewide Respite Care Program (SRCP) is administered locally 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 county coordinator for the program.

Sponsor Agencies

Eleven of the twenty agencies administering SRCP are home health agencies, primarily vendors of home health aide services.[11] County government offices, such as the Office on Aging, represent six of the sponsors; one is a non-profit social service agency, and two are hospitals. Of the twenty respite sponsors, fifteen offices primarily serve the elderly population, while only one primarily serves the disabled.

Coordinators

Eight of the program's twenty-one coordinators are social workers, six are either Registered Nurses (RN) or Licensed Practicing Nurses (LPN), three are licensed in both nursing and social work, one is a home health aide, and four have no formal training in nursing or social work. At the time of the interview, the average tenure period for the coordinators was approximately 7 years, with a range of 2 months to 14 years. Most had experience with long-term care or government program administration prior to becoming coordinator. Six had worked in a long-term care setting, three had administered government programs, and four had done both.

A number of the coordinators see their background as shaping the manner in which they administer the program. For example, several coordinators with nursing backgrounds commented that they are particularly able to understand the medical condition of the care recipient, and that this insight is useful when determining appropriate service plans. Several social workers commented on their emphasis on the social well-being of the clients. This includes enabling the clients themselves to determine how respite can best serve them, with the coordinator providing information and support. One coordinator who is also a manager of the sponsor agency indicated that she has a particularly good understanding of the financial aspects of SRCP.

Coordinators have a wide range of work situations. Only fourteen coordinators are full-time employees of their sponsor agency. Twelve have part-time support staff performing SRCP duties ranging from client assessments to clerical support. Twelve coordinators indicate that they need more help administering the program, with half of those indicating that clerical responsibilities, such as data entry, detract from the time they are available to clients. The possibility that more staff are needed at some local programs is recognized by the DHSS staff.

This need is compounded by the fact that nine of the coordinators have job duties beyond SRCP. Three are involved in upper-level management of the sponsor agencies (all home health agencies), two serve as social workers for non-SRCP clients, and three are involved in administrative duties, agency outreach, or the administration of other government programs such as CCPED (the Medicaid Community Care Program for the Elderly and Disabled).

PROGRAM CONCEPTION

Primary Goal

The majority of coordinators described their primary goal as relieving the unpaid caregiver while improving the quality of life for both the caregiver and care recipient. This entails serving as an advocate for clients, especially by facilitating problem-solving for the caregiver. One coordinator commented, “I try to connect families with competent care that affords caregivers the opportunity to live their lives.” Another coordinator asserted, “Service to my client comes before bureaucracy such as paperwork.” Only one coordinator asserted that her primary goal is to delay the long-term institutionalization of care recipients. Although a number of other coordinators described this objective as important, it is not their primary goal. This emphasis was mirrored by a DHSS staff member, who noted that an additional hope for DHSS and the legislature has been that the program would eventually save money.

Several coordinators emphasized that caregivers sometimes misunderstand the program’s purpose, as well as the proper role of the service providers. One coordinator described caregivers who want round-the-clock services and expect home health aides to do more than they are legally permitted to do. “They [caregivers] are overwhelmed,” she noted.

Primary Client

Both care recipients and caregivers are considered clients of SRCP. When asked, more than half of the coordinators consider the caregiver to be the primary client. Five coordinators believe that both the caregiver and care recipient are the primary clients, but that the emphasis is on the caregiver. As one coordinator described it, “The program’s emphasis is on the caregiver, but the care is focused toward the care recipient.” Another coordinator added, “Everything is based on the caregiver: interests, needs, stresses, willingness, and eligibility.” In contrast, two coordinators asserted that the care recipient is the primary client, and another explained that although the objective of respite is to relieve the caregiver, the care recipient is the client because s/he is in need of the professional attention.

The Implications of Mission for Work

Coordinators described a number of ways in which their perceptions of the program’s goals affect the way in which they conduct their work. Most coordinators feel that the program’s mission requires that they provide flexible, client-oriented service. Coordinators reported meeting clients needs in any way possible. This includes changing service plans when requested to best cater to the specific circumstances surrounding the individual caregiver.

One coordinator noted that caregiver education is an important part of fulfilling her clients’ needs. Better management of the stresses associated with caregiving enables the caregivers to better take care of themselves, and leads to better care for the care recipients. To illustrate how their mission shapes their work, several coordinators noted that in order to best serve their clients, they make efforts to refer them to services outside of SRCP if necessary. (This is in fact an explicit expectation of the program.)

A DHSS staff person described encouraging coordinators to translate the emphasis on caregiver relief into their approach to eligibility assessment and service planning. This individual urges coordinators to evaluate the coping skills of the caregivers, as well as the care recipient’s level of disease or disability. Coping skills—or the lack thereof—are major factors in the caregiver’s emotional wellbeing. “Coordinators need to see that the situation they see as not that bad can actually cause great stress.”

Target Population

DHSS staff noted that the large number of sponsor agencies serving the elderly population reflects and helps to promote a de facto focus on the elderly which has evolved over time and which should be revisited. “They [agencies] should be serving the younger population more, but it’s hard,” this individual commented. Similarly, the staff person spoke of the lack of respite users who care for mentally ill care recipients. “This is also a hard-to-serve population—one which providers are not always comfortable with. County coordinators reach out to the populations that they are most comfortable with or interested in serving.”

Changes in the Program’s Goals

The overwhelming majority of coordinators did not perceive any changes in the mission or philosophy of the program in the time they’d been associated with it. Two coordinators, however, noted that the care recipients have become needier over the years; the program has responded in part by addressing the special needs of older and working caregivers. One coordinator described pushing for cap extensions and allowing clients who enter mid-year to take advantage of services with a full-year budget.

At least one staff person felt that there should be a change in the program’s goals in the future, wanting to see it as a birth-to-death program, providing respite to caregivers who are parents of young children with disabilities as well as caregivers of adults. (The state does offer respite care for all ages through CCPED, and to the developmentally disabled across the lifespan through the Division of Developmental Disabilities. However, as noted, CCPED financial eligibility criteria are more restrictive than SRCP’s and not all younger disabled are developmentally disabled. As will be seen, our analysis of the administrative data lends support to the idea that there is unmet need among the younger disabled.)

Coordinator Role Perception

As described above, coordinators see their role as taking a flexible approach to meeting client needs. In particular, almost every coordinator described serving as a case manager. A DHSS staff member also noted that although the coordinators are not expected to act as case managers, most of them do. This was reflected in their interviews, which addressed various ways in which they help clients put together and maintain a service package that makes sense in the context of their needs and available assistance, and help to connect them to other services when needed. Coordinators described other roles as well, for example, alleviating the apprehension a care recipient might feel when using inpatient respite for the first time.

The Uniqueness of SRCP

DHSS staff and county coordinators noted a number of ways in which SRCP is different from other home and community care programs: the focus on caregivers, relatively few bureaucratic obstacles to program use, and favorable eligibility criteria. Six coordinators noted that a significant difference is the primary focus on caregivers, as opposed to the emphasis of a traditional home health program on providing service to the care recipient. “Respite works with caregivers to maintain their health,” one coordinator explained. “A healthy caregiver is more apt to deal with the problems associated with caregiving.”

Furthermore, certain aspects of program administration, such as the lack of paperwork required for completion by the caregiver, make respite more “caregiver-friendly.” The application process was described as relatively easy compared to the process for other state programs. One coordinator explained that respite is also different from other programs in affording caregivers respite services without the burden of maintaining frequent contact with the program.

Coordinators noted that the eligibility criteria for SRCP are more favorable than those of programs such as CCPED, the Medicaid waiver program, given CCPED's much lower asset limitation. Four coordinators noted that SRCP offers a wide variety of service choices to its clients.

COUNTY DIFFERENCES

Coordinators perceived important differences in program administration resulting from the nature of the agency, county characteristics such as size, and the resources available to the coordinator.

Nature of the Agency

Counties reported differences in obtaining services depending on their broader service mission. For example, home health aide agencies appear to experience greater ease in finding aides to service respite care recipients and several reported being able to get those aides at a better rate. Some home health agencies also report readier access to scarce in-home services, such as companions. Conversely, hospital-based coordinators reported a lack of access to and oversight of home health aides.[12]

Another aspect of mission is the clientele served. More than one staff person commented that because in Bergen county the sponsor is a government agency serving the disabled (a unique sponsor type in the program), this is the county that has the largest developmentally disabled group among its care recipients.[13]

A final relevant dimension of agency type is the public/private divide. County and private sponsor agencies perceive different challenges in their work. Private sponsor agencies reported greater flexibility in contracting with providers. Conversely, some coordinators at government-based agencies feel that government mandates limit their ability to be flexible with clients, thus contradicting the client-oriented objective of SRCP. A DHSS staff member commented that county-based agencies must conform to civil service requirements, potentially limiting the choice of coordinator or creating inordinate delays in filling vacancies. One county coordinator reported a fear among coordinators from private agencies that SRCP is moving in the direction of universal county administration.

Size of the County

Several coordinators from the smaller counties indicated that their size enables them to know each client on a personal level. One could imagine that this personal knowledge improves the coordinator's ability to factor the client's specific preferences and circumstances into service planning and administration. Moreover, these coordinators noted greater ease in conducting assessments. A DHSS staff member commented that a close relationship between the coordinator and her clients is especially evident within the smaller counties. This individual explained, "When coordinators don't do assessments themselves, this leads to a more distant relationship."

Several coordinators from larger counties noted difficulties with travelling to visit clients and conducting outreach. Moreover, they feel there is more unmet need among the more populous counties and the potential for a more extensive waiting list.

On the other hand, some of the smaller counties have fewer service providers, thus further complicating provider access problems (such as the current home health aide shortage). Conversely, larger counties reported a greater wealth of market resources, particularly nursing homes and home health aide agencies.

Resources Available to the Coordinator

Counties differ in the resources available to coordinators. Several coordinators reported taking advantage of sponsor agency public relations staff to promote SRCP. Additional resources reported in individual counties include a free senior companion program, food banks, and "At Home with the Arts," an educational program for caregivers of care recipients with Alzheimer's dementia. The program teaches activities that can be performed in the home to stimulate the care recipient and promote family interaction.

IMPACT OF BEING A SPONSOR AGENCY

Benefits

From the viewpoint of a sponsor agency, the public image and prestige of administering SRCP are the major advantages of being a sponsor. As one coordinator described it, "The community recognition of providing SRCP keeps the agency flowing." A number of coordinators asserted that both SRCP and the sponsors share the same objective, so the program helps to fill the sponsors' mission. Administering SRCP has more concrete benefits as well. One coordinator uses SRCP as an outreach tool for some of the other services offered by the agency, referring clients internally. Several coordinators noted that SRCP directly enables the agency to use its resources. For example, home health aide sponsor agencies often use their own aides primarily to service care recipients. One coordinator added that administering SRCP has increased her networking capacity throughout the long-term care community within her county.

Disadvantages

The large majority of coordinators did not report any disadvantages associated with sponsoring SRCP. Those that were described were exclusively financial. A few coordinators asserted that respite is not a money-making endeavor for them, because the agency must devote employee time to the program and absorb costs that go without reimbursement. Moreover, respite clients sometimes make more demands on the agency's resources than other clients. For example, respite caregivers generally need home health aide services in contiguous time blocks of at least three hours to generate a sufficient break. Also, if the sponsor is also a service provider, the fact that some services are reimbursed at the Medicaid rate is a disadvantage, leading to a smaller marginal profit than results from serving private-pay clients. A DHSS staff member also noted that some agencies may lose money because their staffing costs and other operating expenses exceed the payment they receive to administer the program. This individual feels the county sponsors continue administering the program because they are committed to the respite concept and enjoy its positive image.

Challenges of Being a Sponsor Agency

Database Management with the FACTORS Program

The new database management software program, FACTORS, replaced the old system in 2000. While there has been some praise of the new system, the majority of coordinators described it as an obstacle to their work and reported spending more time on data entry than they had previously. Staff reported difficulties with printing reports, confidentiality restrictions, and other kinks in the system, and some complained that the system was not designed specifically for SRCP. It is too early to tell whether these complaints might not be the result of learning a new system and therefore disappear in time. In the meantime, some coordinators report having to cut back other efforts, for example outreach, in order to devote more time to data management. Moreover, the level of computer proficiency appears to vary among the coordinators, and the degree of confidence with computer-related issues would probably affect their perception of a technical change.

Paperwork

Some coordinators stated that the paperwork coupled with their obligations to the clients overwhelms them. “I often feel pulled in too many directions,” stated one coordinator who feels she is in need of assistance with clerical and assessment responsibilities. On the other hand, another coordinator finds the paperwork for SRCP to be light compared to that of other state programs. One coordinator would like to see the program forms modified, viewing some of the questions as outdated.

Budget Restrictions

Several coordinators reported that their budgets do not permit them to conduct all the activities they would like, such as additional outreach. Furthermore, more than one coordinator commented that increases in the county budget have not matched the rising costs of long-term care services. The perception that there is inadequate funding extends to the DHSS staff as well.

Receipt of Funds Late in the Year

A couple of respondents described dissatisfaction with receiving promised new funds from the legislature late in the 1999 fiscal year, a problem which has occurred only this once. As a result of this late disbursement, one coordinator described difficulty spending all of the money. A DHSS staff member commented, “New money is pressure for the coordinators. It may not be enough to allow them to hire help, but just creates additional pressure.”

HISTORY

In response to interview questions about program history, coordinators highlighted a number of changes in program design, the state and national policy context, and the market that they consider important to program operations.

Changes in Program Design

Key changes in program design noted by the coordinators included expansion of the service repertoire, more flexible eligibility criteria, increased program funding, and the change in the data management system.

Enhanced Service Repertoire

Coordinators saw as an important change the addition of new services such as alternate family care, camperships, and assisted living. An increase in the allowable in-facility stay from 14 to 21 days in 1992 helped caregivers seeking respite for vacation and also increased the willingness of inpatient facilities to contract with SRCP.

The last increase of the service cost cap in 1992 from $2,400 to $3,000 was noted as a significant change by several coordinators. A number of respondents, however, feel that another increase is due.

More Flexible Eligibility Criteria

A frequently discussed change was the modification of eligibility criteria in 1998 to include both spouses' incomes. Prior to this change, the income of only the care recipient was considered. Staff were concerned that this precluded many female caregivers from qualifying for SRCP, as their spouses' incomes were high although their joint per-person income may have been low.

Working caregivers were included in the program around 1992. Several coordinators noted that this change allowed them to serve an extremely needy group of caregivers.

Increased Program Support and Funding

Eight coordinators and a DHSS staff member noted the significance of increased funding, allowing counties to expand their outreach efforts to meet unmet need and reduce their waiting lists. Several coordinators feel as if state and national legislators are paying more attention to the needs of caregivers than previously. "Caregiving is becoming more important to politicians as baby boomers who are caring for their parents are pressing for help from the government," noted a coordinator. DHSS staff and coordinators credit the efforts of consumer advocates such as the Alzheimer's Association.

One individual speculated that the increased visibility of caregiver issues on a national level would lead to a further expanded funding base, thus allowing the state to increase service caps and reimbursement rates. She cited as an example the National Family Caregiver Support Program, which was subsequently passed as part of the Older Americans Act Reauthorization of 2000.[14] Another possibility that emerged from interviews was that new financial resources might be developed that could ultimately allow the program to pay informal caregivers.

A Change in the Data Management Software

As mentioned above, the FACTORS data management system was introduced in 2000, and has proven to be a challenge to many of the sponsor agencies, although perhaps a temporary one.

A Change in Program's Administration

Some respondents described the change in program administration from the Department of Human Services to the Department of Health and Senior Services as reinforcing an already existing emphasis on senior services. A DHSS staff member agrees that SRCP should be serving the younger population more. For example, the program statewide does not really offer much in the way of camperships, which primarily serve a younger, disabled population.

Changes in the State and National Policy Context

Coordinators noted some important changes in the state and national policy context. One was the cessation of home health aide provision by Veterans Administration hospitals. The observed effect was an increase in respite-seeking care recipients previously served by the VA facilities. Moreover, Medicare cutbacks were cited as putting a strain on long-term care programs.

A couple of respondents noted that the recent creation of new home care programs may require some sorting out of who is to be referred where. This is particularly true for Jersey Assistance for Community Caregivers (JACC), which serves the same income group as SRCP. Finally, one coordinator spoke of the pressure she feels in being accountable to multiple programs, particularly with the advent in the past couple of years of the state's Community Choice initiative—a program to move Medicaid clients out of nursing homes that requires finding these clients community-based care.

Changes in the Long-Term Care Market

The most commonly discussed trend in the long-term care market was the current shortage of home health aides and the lack of respite beds in inpatient facilities. The section of this report devoted to services will provide a more in-depth discussion of these shortages. One coordinator noted the push in recent years to move patients out of nursing homes and into the communities, creating an increased demand on caregiver support programs. Another noted the advancements made in the long-term care technology arena such as telemedicine technology, arguing that such technology cannot be utilized by SRCP without a substantial increase in funds.

The advent of assisted living allows the coordinators to reduce the use of and dependence on nursing homes. One coordinator explained that assisted living is cheaper than nursing home stays in her county. Furthermore, assisted living is attractive to care recipients who do not require the level of care offered at a nursing home and are more interested in maintaining a sense of independence. Unfortunately, despite reports from some coordinators that the number of assisted living facilities is on the rise, several coordinators noted that assisted living is still scarce in their counties and/or that many facilities are unwilling to take respite care recipients. There are currently no rates set for assisted living through SRCP, as it is a new service. One coordinator worried that access to assisted living beds will become more limited when SRCP defines assisted living as a standard service and sets a rate for it; however, while assisted living will soon be a standard service, DHSS program staff are not currently planning to establish a fixed rate.

OUTREACH

Client service begins with outreach to the target population. As the discussion will demonstrate, however, coordinators must balance the need for outreach with other real-world considerations.

Advertising the Program

Coordinators take a variety of approaches to advertising the program. The overwhelming majority distribute brochures at health fairs, and to social service groups, service providers, community medical professionals, and hospitals. Others take advantage of the outlets of sponsor agencies, such as bulletins or agency advertisements. Some encourage respite clients to spread the word. Community resources are also popular media. These include church bulletins, senior newspapers, local newspapers, Alzheimer’s support groups, and county cable television. Moreover, a simple and potentially effective method employed by one coordinator includes the use of the discharge planners at local hospitals to identify prospective respite clients and provide them with basic information. Three coordinators noted that they do not currently conduct any advertising, either because the agency does not need to advertise, they do not have the funding, or they lack the time and personnel to launch an effective advertising effort. A concern of the authors is that by not advertising these coordinators might not reach the neediest, least socially-connected people. On the other hand, there are reasons why coordinators choose not to advertise in the face of budget limits. A DHSS staff member noted that there is generally a lack of aggressive advertising currently, as coordinators are reluctant to overstimulate interest and create a waiting list for which they will not be able to provide service. “The coordinators face an ethical issue of raising family expectations.” One coordinator also noted that she restricts outreach because she is concerned about overspending, as this would be a problem for her agency; however, in recent years, the DHSS program office has had sufficient funds to offer sponsor agencies the assurance that they could cover an unforeseen overage.

Perceived Limitations on Outreach Efforts

Several coordinators note that it is not possible to reach everyone who qualifies for SRCP in the county. Their interviews reveal a variety of reasons and possible reasons for this belief: a lack of time, the feeling of being overwhelmed experienced by some coordinators, the lack of support staff at some county agencies, and insufficient funds in some county budgets to support more extensive outreach efforts.

One coordinator from a large urban area cited special difficulties reaching qualified candidates due to the magnitude of needy, lower income caregivers in her area. Another coordinator stated that low-income minority groups residing in inner city neighborhoods tend to be missed by more mainstream methods of outreach. Her office does not make any efforts beyond regular advertising and outreach to increase enrollment among this population.

Outreach Among the Younger Disabled and Mentally Ill

As noted earlier, a DHSS staff member described outreach among the younger disabled and mentally ill as varying depending on how interested and comfortable the sponsor agency is in serving this population. This staff person expressed a desire to see more outreach to these populations and to find service providers to work with them. Interestingly, among coordinators, there was little discussion of outreach efforts to increase care recipient enrollment among the underrepresented groups of younger disabled and mentally ill.

Sources of New Clients

The overwhelming majority of coordinators say most new clients come from referrals from either a government agency (e.g., Board of Social Services), service provider, or a health professional. One coordinator who also conducts home care social work for the sponsor agency described “self-referring” clients to SRCP. Interestingly, few coordinators directly attributed increased enrollment to outreach at health fairs, Alzheimer’s support groups, or long-term care facilities. Although intake forms include a question on how clients learned about SRCP, currently, no coordinators have aggregated and analyzed statistics on referral sources. Such information would help identify effective outreach mechanisms.

ELIGIBILITY

Clinical Assessments

Once clients come to SRCP, eligibility is determined through clinical and financial assessment. Program coordinators determine clinical eligibility based on assessment forms that delineate the relevant dimensions of the clinical evaluation, and on diagnoses obtained from a physician. The final determination of clinical eligibility takes into account the coordinator’s assessment of the case as a whole.

The majority of the sponsor agencies (17) conduct the initial clinical assessments themselves, and the respite coordinators working for the sponsors usually serve as the assessors. Three sponsor agencies contract with outside agencies, and one works with outside agencies, as well as drawing on their own personnel. Out of the seventeen sponsor agencies that conduct their own assessments, thirteen have the coordinator perform the assessment. These thirteen coordinators include social workers, RNs or LPNs, RN/social workers, one home health aide, and one individual with no formal training or license. One of the social workers volunteered that she is uncomfortable performing the assessments without the assistance of a nurse or medical professional, as she is unfamiliar with some of the medical conditions ailing her care recipients. Only two of the thirteen coordinators call upon the assistance of either a per diem registered nurse (RN) or a full-time sponsor-employed social worker.

The four agencies that conduct their own assessments but do not use the coordinator as the assessor either employ full-time/part-time RNs or contract per diem with social workers or nurses. In fact, one agency has a full-time social worker on staff whose principle function is to serve as the respite assessor. The county coordinator in that agency explained that having a full-time assessor, whose primary responsibility is to be out in the field, allows her to handle incoming phone calls and deal with caregiver concerns and/or emergencies in a timely manner. She further commented, “Clients are more comfortable knowing that someone is always at the agency to assist them during business hours.”

Four agencies subcontract the assessment of clients to other agencies or professionals, with one coordinator periodically conducting the assessments herself. For example, two agencies subcontract with a specific nurse or social worker employed with another agency. Hence, the arrangement is close to a consulting contract. The other two sponsors contract with agencies (e.g., a home health agency) that provide them with the nurses who perform the assessments. Therefore, the former arrangement involves the consistent use of the same individual to assess prospective clients, whereas the latter draws from the personnel working for the subcontracted agency.

All coordinators noted that, as was designed, initial assessments are generally conducted in the care recipients’ homes. One coordinator commented that she offers to meet with the care recipient and caregiver wherever it is most convenient for them. Occasionally, another coordinator meets clients at day care, and one welcomes clients who prefer to come into the office.

Although one coordinator described the reassessment process as “on the back burner,” as she is without a support staff and has to concentrate on initial assessments, the rest of the coordinators report performing the reassessments every six months, as is program policy. Ten of the seventeen conduct the reassessment by themselves, whereas the remaining seven use the help of a full-time staff social worker, per diem RN, or a part-time staff RN. Three coordinators do not perform the reassessments, and recruit per diem social workers/nurses or have a full-time staff social worker serving as the assessor. Reassessments are conducted primarily over the phone. Three coordinators noted that they alternate home visits with phone calls every six months, and two make occasional visits to the care recipient’s home. A few commented that they would make a home visit if the situation called for one, e.g., if they were made aware that services being rendered to the care recipient were inappropriate

Only three coordinators never reassess over the phone and will meet the care recipients in their homes, at their day care centers, or at a venue that is most convenient for them. One of these coordinators commented, “I never conduct a reassessment over the phone. It is a lost opportunity to assess the home life and observe the interaction with the caregiver and care recipient.” Another coordinator commented that a home visit allows the reassessor to see the patient’s medical condition and medications. If medical attention is needed, she is in a position to refer the care recipient to appropriate medical care.

Financial Eligibility

A number of coordinators suggested reform of the eligibility criteria. In fact, some coordinators described the income and asset criteria to be an obstacle to their work. For example, several coordinators argued that the current criteria do not account for the expenses incurred by the family in caring for someone with a chronic illness. In this regard, one coordinator noted, “Once a client makes it into the program exceptions can be made to account for financial hardships. But this is only after someone has been accepted into the program." This effect is more profound for care recipients who are just on the borderline of eligibility, notes another coordinator. One coordinator suggested conducting case-by-case reviews of applications. Another coordinator would rather see 100% cost-share than have to impose income requirements on prospective clients. "Those who substantially exceed the income requirements should be allowed to take advantage of the case management and support offered by respite at a 100% cost-share." In fact, this proposed policy change was already being considered.

Although six coordinators noted that the inclusion of working caregivers into SRCP represents one of the most substantial policy changes in the program's history, several coordinators would like to see more flexible criteria for working caregivers. One coordinator explained that, because working caregivers go to work, then come home to caregiving responsibilities, they are in greater need of respite care than others. The fact that a spouse works, however, can preclude a couple's eligibility, as their income is likely to be higher than that of a dyad with a non-working caregiver.

Although several coordinators noted that the SRCP asset limitation of $40,000 is more liberal than that of the Medicaid waiver programs, several coordinators believe the limit should be raised. One coordinator argued that it should be doubled in order to parallel the policy change that allowed for the consideration of both spouses' incomes for eligibility.

Waiting List

The majority of counties have maintained waiting lists in the past or currently do so. They take clients off the list when the funding or resources become available to serve them, e.g., when care recipients die or withdraw from the program. One county uses cost-share funds to provide services to wait-listed care recipients. Several counties report using the caregiver waiting list prioritization form provided by the state to create priority rankings. Some take into consideration the severity of the care recipient's medical condition. In one county, a coordinator, who is a social worker, assigns the highest priority to care recipients who are referred from Adult Protective Services (APS); her background may lead her to give more consideration to a family in a situation of domestic turmoil. In addition, a few counties volunteered that they had taken advantage of the option of offering services on an emergency basis, and two counties have used Alzheimer's Association funds to serve more care recipients. Four counties almost never have a waiting list, one county has never had a waiting list, and another county has not had a list since the state increased its budget.

SERVICE

Service Types

Although the demand does not exist for all services in each county, almost all of the counties offer or can offer every standard service. For example, few counties have a demand for campership services, but several coordinators noted that they could arrange for the service if the need should arise. In several counties, however, the lack of service providers prevents the provision of services such as alternate family care, companion services, assisted living, and medical day care. Furthermore, several counties that provide the aforementioned services still face a scarcity of providers in the county. One county that strongly believes in the value of social day care is fearful that these agencies will convert to more comprehensive medical day care centers, which are more expensive. On the other hand, several providers noted that less comprehensive services such as social day care and companion services are not appropriate for many of the respite care recipients. This holds especially true for care recipients suffering from severe chronic disease requiring medical attention or from late-stage Alzheimer's dementia.

Interestingly, the large majority of counties describing problems with scarcity of services—especially home health aides, nursing homes, and medical day care facilities—represent the lowest third of counties with respect to population density.[15] Less densely populated counties may have trouble attracting home and community-based suppliers due to the sparse and dispersed market.

A number of counties reported problems obtaining services due to the low Medicaid rate, which deters some providers from contracting with SRCP. In addition, one county reported difficulties finding nursing homes due to a reluctance to accept care recipients for limited periods of time.

In addition to the traditional respite services, some counties take advantage of volunteer or free services available to respite care recipients, including free social day care, volunteer companion services, and the Alzheimer's Association's "At Home with the Arts Program."

Contracting with Vendors

Virtually all of the sponsor agencies maintain contracts with their service providers. Two counties also use non-contracted agencies at times if the rates are reasonable. One sponsor agency does not maintain any contracts, but deals with agencies on a case-by-case basis. This arrangement, however, makes sense since the sponsor agency itself provides 95% of the services administered to the respite care recipients.

DHSS staff commented on the advantage of having local agencies deal with the service providers. "They know the services that are available in their community better than Trenton does." Moreover, this individual noted that the coordinators are better able to evaluate the effectiveness of services, because they hear from dissatisfied clients and can survey consumers. Also, many of the coordinators know the providers personally.

Choosing Service Providers

The nature of the sponsor agency (e.g., county vs. private) and the availability of providers in the county place restrictions on county coordinators in obtaining services. For example, one county-based sponsor agency must use providers on the Medicaid list. On the other hand, a private sponsor agency located in a less dense county has few choices with respect to providers.

Two of the more popular methods used to solicit new contracts include personal contact with the directors of new facilities or the use of a formal request for proposal (RFP). Seven coordinators reported visiting new facilities in person. Several coordinators noted that they especially try to court facilities that are recommended by care recipients or their families. One coordinator uses the Medicaid list of vendors when looking for new providers. Coordinators shared a number of "principles" of contracting including the need to maintain continuity among contracted providers, contracting based on the need for a service, and willingness to contract with every vendor in the county. Contingency planning by several coordinators includes contracting with providers outside of the county in case of emergencies and using non-contracted providers if the rates are reasonable.

Each county utilizes the services of approximately 17 agencies on average. Every home health aide sponsor agency uses aides from that agency. However, one coordinator noted that although she tries to assign her agency's aides to SRCP clients, she would not hesitate to use the services of another home health aide agency. Moreover, another coordinator actively uses other home health aide services in order to give her clients more options. Three sponsor agencies use their own companion services, and one agency uses its own medical day care service, as it is the only medical day care provider in the county.

Competition and Turnover

Sixteen coordinators have observed little to no competition among the service providers in their counties. The lack of competition is attributed to a shortage among providers such as nursing homes, home health aide agencies, and medical day care facilities. Five coordinators reported some competition, as there are many new facilities in their areas or pockets of facilities. Almost all of the coordinators have witnessed little-to-no turnover among the agencies they use. One coordinator stated that the rare termination of a contract is usually due to dissatisfaction with the rates.

Oversight Over Vendors

The majority of counties employ a method of direct oversight and/or maintain frequent contact with care recipient families in order to monitor the service providers. Direct oversight includes unannounced spot checks, coordinator management of in-house providers employed by the sponsor, use of sponsor agency nurses to check on home health aides, and frequent communication/ meetings with facility directors. In one county-based sponsor agency, a mandate requires that county-employed monitors visit all vendors quarterly. Frequent communication with the families occurs during reassessments, client-initiated contact, feedback from satisfaction surveys, visits to the families while the care recipient is in an inpatient facility, or discussions with care recipients upon immediate discharge from a facility. Four coordinators noted they often visit a facility upon the receipt of a complaint from a client. Another coordinator noted that the feedback received from clients is taken into consideration upon the renewal of service contracts. Moreover, coordinators who serve in a management capacity at the sponsor agency report having excellent control over providers employed by their agency. In one instance, the coordinator can directly observe services being rendered on the premises. Four coordinators look at the credentials (e.g., JCAHO certification of nursing homes) and proof of insurance of their providers periodically. One of those counties does nothing beyond checking the credentials. In addition to credential checks, the majority of coordinators are aware of regular agency-initiated checks of their own individual providers (e.g., home health aides).

In one county, fiscal oversight is facilitated by the county's arrangement with service providers, authorizing services for a year at a time and requiring the providers to manage the service provision according to the budget. By the nature of this arrangement, the coordinator can cross-check her records against those of the providers in order to verify their record keeping and billing accuracy.

Relationship between the Program and the Service Providers

All coordinators reported positive impressions of their service providers. They described open lines of communication, a willingness to work with SRCP, and consistent, quality service. One coordinator noted that their vendors will try to get them services when they are hard to find. "Our service providers will work with us when we have no other alternatives." Another coordinator actively cultivates good relations with her providers, believing it will ultimately affect the service to her care recipients. Moreover, one coordinator describes her concern for her providers' employees; she will not send providers to a home that is not suitable for home health care.

On the other hand, several counties reported some disadvantages to the service provider-program relationship. Specifically, one coordinator is disconcerted by the unwillingness of nursing homes to reserve beds for respite care recipients, due to the higher rates paid by private payers. Other coordinators notice that some providers can be inaccessible, unreliable, and inflexible at times. Furthermore, provider agencies that fail to communicate agency or care recipient-initiated changes in the service plan hamper the coordinator's ability to effectively manage the care recipient's care.

Relationship Between the Providers and the Clients

According to coordinators and DHSS staff, the vast majority of service providers maintain positive relationships with the respite clients. Eight coordinators state that they make active efforts to mediate the relationship between the providers and the clients. Several coordinators described certain administrators of the provider agencies as maintaining contacts with the families as well as keeping the coordinators apprised of any new developments with the care recipients.

Several advantages to good provider-client relationships were noted, some specific to the type of service. For example, a good relationship with a home health aide leads to a greater continuity of care. Several coordinators have care recipients who have been under the care of the same aide since they entered the program. A positive experience with a nursing home enables the care recipient to gain familiarity with the in-patient environment.

Occasionally, some coordinators field complaints from the clients about providers. Several coordinators noted that the relationships that do go sour are often due to the client's behavior as opposed to the agency's. For example, one coordinator stated that the occasional complaint often results from a client's misunderstanding of the service parameters (e.g., definition of light housekeeping). Another coordinator feels that personality conflicts between a provider and client sometimes preclude a good working relationship. In such instances, the coordinator will do her best to match the client with a more compatible provider. Interestingly, one coordinator described instances where the care recipient likes the provider, but the caregiver does not. This coordinator feels it is more critical to make the care recipient comfortable with the new environment or care situation. Hence, she will always urge the caregiver to try to make it work in these cases.

Developing Service Plans

Counties define a specific service plan for their care recipients upon the initial assessment. State policy is that reassessment of the client and the plan should take place every six months, although a few counties tend to reassess annually. Several coordinators commented that they always encourage the client to choose a service plan. One coordinator urges her clients to commit to a plan even if they only plan to use respite once a year for vacation. However, most coordinators noted that they are flexible with respect to requests for modifications to the service plan, as the client situation can change at any point in time. In service planning, coordinators' varying views of the "client" emerge. For instance, several coordinators specifically cater the plan to the needs of the caregiver, while another coordinator places more emphasis on the medical needs of the care recipient.

The process of deciding on a service plan involves the coordinator explaining the services available and the amount of care that can be provided under each service given the cost cap. Moreover, several coordinators suggest services that they feel make the most sense considering the clients' specific situations. The overwhelming majority of the coordinators state that they base their service recommendations on the needs and wants of the clients, noting that most caregivers know what they are looking for before they come to SRCP. One coordinator encounters caregivers who want the agency to make all of the decisions. She brings the caregivers back into the process by encouraging them to chose services that best satisfy their needs. Additional sources of information and input used to decide on a service plan include the assistance of a social worker, referrals, observations made in the care recipients' home during initial assessments, and the financial resources at the care recipient's disposal.

Once the service plan is established, clients can have the plan modified, as long as their requests are compatible with their service caps and the available resources. One coordinator argued that the flexibility of SRCP is what has made it as successful as it is. One coordinator calls her clients every three weeks to determine if the services rendered are appropriate, in order to facilitate a change in the plan if necessary. Three coordinators inform the service providers of the authorized services for each care recipient, thus ensuring that clients must contact the coordinators prior to changing the existing plan. Only one coordinator feels that service plan deviations are difficult, as they typically occur during times of crisis, requiring services that are often unavailable. This coordinator usually resorts to finding another family member to care for the care recipient in such instances.

Ad Hoc Services

Most coordinators reported that when they do provide services on an ad hoc basis, it is in response to a caregiver emergency, a caregiver's need for vacation, a change of service preferences, or a change in the care recipient's condition. Several coordinators commented that they infrequently provide services using an ad hoc arrangement, and one coordinator reported that ad hoc arrangements complicate the management of the clients' budgets. Another coordinator encourages her ad hoc clients to use respite services on a regular basis as opposed to saving the services for times of turmoil. The state program office is flexible with respect to service cap limitations for clients experiencing an emergency.

The large majority of coordinators play an active role in helping clients decide on ad hoc services. Several coordinators say that although they have good insight into the needs of the clients, they prefer that the clients make final decisions regarding the particulars (e.g., the specific facility); they see their job as providing all of the necessary information, offering options based on the resources available, conducting evaluations with their ad hoc clients to determine the appropriateness of service requested, and providing clients with information about available providers. One coordinator takes care of every aspect of the process for the client, while at the other end of the spectrum another allows the client to make the arrangements on his/her own by pre-authorizing service options with a provider ahead of time. The rationale behind the latter approach is to facilitate the provision of service with short notice.

Most Effective Services

The overwhelming majority of coordinators have opinions as to which services are working best for their care recipients. Home health aides, day care, and inpatient services were the services most often perceived to be particularly effective. Several coordinators favor day care, as it offers sociability, stimulation, and good meals, and offers the greatest duration of care for the respite dollar. One coordinator explained, “Social day care is cheaper than medical day care, and a good number of my clients do not need the extra service that medical day care offers.” However, several counties serving care recipients with late stage diseases do not feel that social day care is the most appropriate service, as their care recipients require a much greater degree of medical attention. Inpatient services are most popular with some coordinators, as they offer a true break to the caregiver and sociability for the care recipient, and familiarize the care recipient with the nursing home environment. Interestingly, one coordinator attempts to convince caregivers to opt for inpatient services, as home health aides are often unreliable and do not show up. This coordinator commented, “If the caregiver is relying on someone to come who might not be able to make it, then it is more trouble than it is worth.”

Camperships are cited as best serving the developmentally disabled. Several coordinators feel other non-traditional services, such as “At Home with the Arts” and “Meals on Wheels” serve their clients well. The coordinators who were unsure of which services work best stated that clients' needs vary widely.

The majority of coordinators who have service preferences base their views on client evaluations, personal communication with clients, and observations made during assessments. In addition, two coordinators tend to recommend the services that offer the most attention for the money. One coordinator described her caregivers as knowing exactly what service works best for them.

Management of the Service Plans and Usage

The majority of counties manage care recipients' service expenditures by comparing the service plans to the cost cap periodically and making adjustments depending on the service usage over the course of the year. For instance, one coordinator adjusts service caps downward for those care recipients who do not spend half of their allotment by the middle of the year. Another coordinator will strongly encourage care recipients who do not spend their budgets to either use the service or defer their funds to someone on the waiting list. Furthermore, coordinators try to pace service usage such that the funds last until the end of the year. One coordinator, however, noted the difficulty of managing clients' records regularly due to the depth of her caseload.

An interesting arrangement places the onus on the service provider to manage service usage, thus effectively shifting the responsibility away from the sponsor agency. Several coordinators submit authorized service allotments for individual care recipients prior to the start of the year. The providers are responsible for ensuring that care recipients do not overutilize services. If the care recipient incurs expenses in excess of the service cap, then the service providers are responsible for the difference. One coordinator updates providers mid-year as to the remaining funds in each account.

Regarding the scheduling of services for the next year, all of the coordinators use information from the preceding year, such as service rates and individual care recipient service usage. Several coordinators make efforts to include anticipated service rate increases as well as changes in their clients' preferences for services into their planning efforts. Several coordinators regard planning to be a high priority, as it facilitates their spending of the entire county budget.

The overwhelming majority of counties increase their client caseloads with funds left after care recipient withdrawal or death. Some counties extend the service cap for care recipients. One county noted that it has not been able to use these funds, as it does not spend the entire general budget.

Cost-share Revenues and Service Provision

Coordinators are allowed to use cost-share revenues as they choose within the context of state guidelines, and can request approval of other uses. They report a variety of uses for the money. In fact, a DHSS staff person noted that coordinators are encouraged to come up with new ideas. Funds are often used to extend the cost cap for needy care recipients or for those in a state of emergency. Several coordinators have increased their caseload with cost-share monies. On the other hand, one coordinator described her reluctance to take on new clients with cost-share. “If I cannot guarantee the money to these clients next year (a function of the county budget), then I will not put people on the program just to take them off the following year.” Instead, this coordinator chooses to increase provision of service for existing clients.

Non-traditional respite services have been subsidized with cost-share. This includes bathing and house cleaning services, the “At Home with the Arts” program, transportation to and from service providers, and support groups for caregivers. In some instances, cost-share was used to provide emergency care to individuals who had not formally applied to SRCP, but were eligible. Moreover, per diem nurses conducting oversight of home health aides and social workers performing assessments have been paid from these funds. Some coordinators have conducted additional outreach, such as advertising in newspapers or sponsoring picnics for community caregivers. Additionally, various equipment and medicines have been purchased, including caregiver training tapes and prescription drugs needed during inpatient stays. Interestingly, one coordinator uses her cost-share to fund the education of home health aides to supply desperately needed aides in her county.

Expenditures and the Service Cost Cap

The vast majority of counties say most of their care recipients are using services to the maximum limit defined by the cost cap. Reasons for not spending to the cap include a limited need for service, death of a care recipient, service provision from a more extensive program, use of services for a vacation only, and entrance into the program mid-year. One difficulty coordinators can face is clients who would spend to the cap too quickly and who must be encouraged to spread out their funds to last for the entire year. One coordinator reported difficulty in particular in persuading users of day care to ration their services. However, the state has created a plan by which users of medical day care can use two sessions per week, thereby spending to the cap by mid-year, and have the rest of the year's sessions paid for half by cost-share funds and half out of their own pockets. This was done in response to a concern that one session of medical day care per week was more disruptive to a client's routine than helpful.

Limitations on Service Provision

Service Cost Cap

The overwhelming majority of staff asserted that the current cost cap of $3,000 per care recipient needs to be increased. While coordinators can request that the cost cap be raised for individual care recipients, most would like to see the standard cap raised. One coordinator commented, "It seems that all of the coordinators want to be able to give the clients more than we are currently giving, but that is impossible with such a low cap." Another coordinator argues that care recipients are receiving less care over the years, as the historical increases in the cost cap have not been commensurate with the rising costs of long-term care. As noted earlier, using average service rates, the cost cap of $3,000 provides four hours of home health aide care, two sessions of social adult day care, or one session of medical day care per week. Several coordinators do not feel that this is enough respite, especially for working caregivers and caregivers of care recipients with Alzheimer's dementia. One coordinator cited statistical evidence that an increase from one to two days of [medical] adult day care would provide a more beneficial respite outcome.

Reimbursement Rates

A majority of counties expressed a concern that the current Medicaid reimbursement rates used for respite service providers are too low, creating a reluctance to serve SRCP clients. One coordinator feels that a higher rate in times of client emergency would make the difference between obtaining service and not obtaining service. With regard specifically to institutional care (as opposed to home/community-based services), it should be noted that Medicaid rates are probably less of an impediment to securing a nursing home stay currently than they were in the past, as there is now a high vacancy rate for Medicaid beds. (The program can pay the private rate at a non-Medicaid nursing facility; however, if the facility accepts Medicaid patients, the program is limited to reimbursing it at the Medicaid rate.)

Length-of-Stay

While reimbursement rates may now be less of a concern for institutional care, there can be other impediments to nursing home access. As noted earlier, one coordinator described some nursing homes as reluctant to fill beds with short-term clients.

Provider Supply

Provider supply can be another impediment to service acquisition. As described earlier, coordinators noted shortages of services in their communities, including companion services, nursing homes, and adult day care facilities. SRCP has particularly felt the effects of the recent home health aide shortage. Several coordinators explained the shortage to be a result of low wages, limited hours offered to aides, and the failure of prospective aides to meet the state's licensing criteria. Consequently, many aides are switching careers and fewer prospective aides are completing the necessary training. To further complicate the shortage, other state programs such as CCPED and JACC compete with respite for aides as well as other services in demand. A coordinator argued that she should be allowed to use uncertified home health aides who are trained by the sponsor agency, especially to perform the less intensive duties, such as light housekeeping, that would traditionally be done by a homemaker. She explained that these aides would be less expensive and more available. She commented that the state's mandate requiring certification further exacerbates the home health aide crisis.

INTRAPROGRAM RELATIONSHIPS

Coordinators described the DHSS program office functions as facilitating problem-solving, providing guidance and clearing exceptions to program rules. For example, coordinators must receive permission from the DHSS program office in order to extend a service cap for an individual care recipient. Through telephone calls, email, and correspondence, contact between DHSS staff and coordinators takes place on these occasions and when information or guidance is needed. Scheduled quarterly, program meetings are also a forum for coordinator-to-coordinator contact, attempting to bring all of the coordinators together with DHSS staff to discuss current issues and address specific problems.

Coordinator Relationships with the DHSS Program Office

Contact

The large majority of coordinators (14) speak with the DHSS program office staff at least once a month in addition to the quarterly meetings and for some contact is virtually daily. At the other extreme, one coordinator reported going months without contacting somebody from DHSS. A DHSS staff member noted that, although they begin with a schedule of quarterly meetings, they know that coordinators are pressed for time and will not hold meetings when there is not much need.

The meetings focus on policy issues encountered by the coordinators. Eleven coordinators as well as a DHSS staff member noted that cost cap extensions or cost-share reductions usually prompt coordinators to contact DHSS. Several coordinators also commented that issues with database management, such as nuances with the FACTORS program, require frequent communication. Individual coordinators noted requiring state assistance for requests for non-traditional respite services (e.g., transportation), grants, and approval requests for assisted living.

DHSS Staff Perspective

One DHSS staff person gave high marks to the sponsor agencies. Historically, those deficiencies that have occurred have included delays in reporting information, failure to meet deadlines, inaccurate data entry, failure to spend all of the funds allotted, and a failure to fill key staff positions. The staff person further explained that the DHSS program office tries to work with the coordinators and support them, for example, by meeting the training needs of the counties and sharing information with them. Moreover, the DHSS staff has worked with the coordinators to help resolve issues with the sponsor agencies. An administrator also noted that cost cap extension requests are rarely denied.

Despite these positive descriptions, one respondent expressed the need for more DHSS oversight of counties, and more uniformity among them. This goal is hindered because DHSS staffing has been cut due to state restructuring. "We could do a lot more when we had more DHSS staff."

Coordinator Perspectives

Like the DHSS administrators, most coordinators commented that the relationship with the DHSS staff is working well and is a positive aspect of SRCP. The commentary described the staff as a helpful, friendly, knowledgeable, accessible, and compassionate resource that is client oriented. One coordinator described DHSS staff as maintaining consistency in the program throughout various changes in the program's structure. Most coordinators described the support, level of commitment, and oversight as the major advantages of this relationship. For example, one coordinator described instances of a DHSS staff member working with county boards to gain more staff time to support SRCP.

Moreover, the coordinators provide a required audit to the Division of Senior Affairs in order to demonstrate the appropriateness of service provision and ensure that cost-share funds are being collected. Several coordinators explained that oversight promotes a sense of accountability for their counties. "With more oversight, the DHSS program office can guarantee more uniformity among the counties."

One coordinator explained that no policies are implemented without fair warning from the state. "We are all very much connected. There's continuity with SRCP as well. They don't change a policy and not let you know about it." Interestingly, a coordinator who has experience administering SRCP in addition to other government programs noted the high degree of organization in this program, especially with respect to the management of data. Furthermore, she described DHSS staff as taking the time to explain how mistakes should be remedied, rather than simply "writing them up" without providing the opportunity for learning.

On the other hand, a few coordinators have concerns about their relationships with the DHSS program office. For example, one coordinator would like more support for new staff. Another coordinator described different perspectives between DHSS staff and those of coordinators because of their different roles. One coordinator feels the requirement to obtain authorization from the DHSS program office before using cost-share funds in unique ways to be unnecessary.

Relationships Among Coordinators

The majority of coordinators (13) feel they have ample opportunity to establish contact with their colleagues. Several noted the courtesy and timeliness in returning messages evidenced by fellow coordinators. Among the coordinators who feel there is a lack of adequate opportunities for contact, several expressed the need for more meetings, more emphasis on professional development, and venues that mitigate the travel burden for coordinators traveling longer distances.

The degree of actual, as opposed to potential, communication varies among coordinators. For example, several coordinators maintain a personal relationship with one another. One coordinator noted that she would contact others who have dealt with similar experiences to hers. She explained, " The contact offers us (the coordinators) the chance to share hardships, offer insight, and compare differences. The meetings are very educational." Common issues that prompt contact among coordinators include problems with the FACTORS software, the need to obtain services for a care recipient in another county, and courtesy calls that facilitate the transfer of a care recipient from one county to the next The large majority of the coordinators expressed that contact among their colleagues is important to their work. They appreciate the reassurance of knowing that their peers are available to help if needed. Moreover, they benefit from the interaction, as it is educational and provides the ability to exchange ideas. When asked if coordinator contact leads to "best practice learning," a DHSS staff member noted this to be the case. Several staff specifically mentioned the quarterly meetings as a productive opportunity to share problems.

Several coordinators, however, do not feel that this interaction is important for meeting their objectives. One coordinator commented, "It is not necessary to perform my job, but it is nice to have the opportunity." One coordinator explained that coordinators do things differently, and face different circumstances. Another coordinator usually directs her questions to the DHSS program office first before seeking the assistance of a colleague.

Despite these dissenting views, most coordinators see a value in contact with their colleagues and the diversity of approaches to program implementation among the coordinators suggests the value of this contact for sharing successful strategies.

PROGRAM-CLIENT RELATIONSHIPS

The overwhelming majority of coordinators 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. One coordinator noted, "After clients die, family members still call. It's nice to know that we (coordinators) have been part of the family." The majority of the coordinators feel that clients are dealt with with honesty, empathy, open lines of communication, a client-oriented relationship, and flexibility. The flexibility lies in the lack of stringent medical criteria for eligibility and the plethora of options provided by SRCP. Such advantages facilitate the development of trust and confidence in SRCP.

On the other hand, a coordinator described clients who receive their services and expect no more. "They treat respite like a job; they do what they have to and then they go," she explained. In her opinion, if this is how the client can best take advantage of SRCP, then a lack of involvement does not have negative implications. Moreover, several coordinators added that the care recipients are often not aware of the coordinators due to their mental status.

There is some client dissatisfaction with the program and several coordinators attribute this disappointment to cardinal misconceptions of SRCP. "Many of the clients are extremely needy and they do not understand that respite exists to offer them a little break," according to one coordinator. Another coordinator added that many clients do not understand the objective of respite and confuse it with home care. For example they expect services to be rendered based on the severity of the care recipient's ailment; such an expectation would be appropriate for a home health care program. Moreover, as respite care might be the only relief offered to the caregiver, their expectations may exceed the capacity of the program. Although sponsor agency staff will attempt to connect caregivers to other services, disappointment may remain.

Disadvantages of the program-client relationship include strong emotional ties to the clients that are emotionally taxing for several coordinators. One coordinator commented, "Performing all of the home assessments forces me to see too much. It is difficult to think with my head, and not my heart." Furthermore, client dissatisfaction with the service providers can make it challenging to serve the client's needs. Also, several coordinators noted that clients may have other demands on their time that make it difficult from them to get in contact with the program when they need to.

PROGRAM IMPLICATIONS FOR THE CLIENT

Timing of Entry to Respite

The large majority of coordinators, especially those who primarily serve elderly populations, feel that caregivers seek respite care during the late stages of the care recipient's condition.[16] "Caregivers tend to come late when they are stressed to the max." Several coordinators think this occurs because caregivers feel uncomfortable asking for what they consider to be charity, families do not realize what is wrong with their loved one, or caregivers wait until they have no other alternatives. Interestingly, one coordinator noted a gender difference with respect to the timing of respite requests. She described older female caregivers as seeking respite only under extreme duress. In contrast, male caregivers call much sooner. One coordinator noted that hospitals are discharging the chronically ill more quickly, thus leading to caregivers seeking respite care for a more sickly care recipient population. Another coordinator explained that late entry leads to a higher turnover rate among clients within the program, as clients require more extensive service or inpatient placement, or die. Several coordinators, on the other hand, described a client population that enters the program during the middle stages of disease. This is especially seen among dementia patients and following a sudden medical complication that affects mental status (e.g., stroke). Perhaps the caregivers of clients experiencing sudden traumatic medical events are more predisposed to seek respite care earlier, as they witness a rapid deterioration of the care recipient's condition.

Unfortunately, few coordinators are approached by caregivers who are planning ahead and come to speak with them as soon as they assume caregiving responsibilities. More commonly, clients seek respite in times of desperation, a crisis, or a worsening of their own health. Most coordinators agree that earlier respite would probably be beneficial to both the caregivers and care recipients.

Perceived Benefits of SRCP

Perceived Benefits for the Caregivers

The overwhelming majority of coordinators agree that SRCP meets its objective of providing some relief to overburdened caregivers. According to the coordinators, caregiver relief comes in the form of being able to participate in caregiver support groups, free time to attend to their affairs, the return of quality time to the family, relief from the guilt associated with the limited capacity to help a sick loved one, and peace of mind knowing the care recipient is receiving good care. Several coordinators noted some additional advantages, including the money saved for the clients' families. Effectively, the break to the caregivers affords them the opportunity to better take care of themselves, thus potentially enhancing their abilities to serve as better caregivers. One coordinator commented, "Now when the daughter goes to visit mom, it's a visit, not a chore."

DHSS staff and coordinators perceive benefits stemming from the flexibility and responsiveness to individual needs demonstrated by the coordinators. For example, a family wanted to bring the care recipient on vacation to North Carolina. The coordinator made the arrangements for respite service down there. A DHSS staff person commented, "There's a committed network of county agencies who know their clients and are active advocates for them."

Perceived Benefits for the Care Recipients

The most commonly mentioned benefit to the care recipients was the social and medical attention offered. Moreover, many coordinators added that the care helps to improve the recipients' quality of life. Several coordinators noted that the care recipients need a break from the caregivers too, thus leading to better relationships between them. In addition, a few coordinators mentioned that the program helps keep care recipients in their homes and maintains their sense of independence.

Satisfaction Surveys

Just over half of the coordinators utilize a client satisfaction survey to gain feedback on the program's administration on the county level, service provision, and effectiveness (see Appendix II, page 53). Survey formats include open-ended questions as well as the evaluation of specific areas using yes/no responses (dichotomous), four, and five point scales. A DHSS staff person would like to implement a policy requiring all counties to conduct surveys, as this individual is concerned that there is not more uniformity among the counties in this regard. Six coordinators implemented satisfaction surveys that have sections specific to the service rendered to each client. Five coordinators take advantage of the sponsor agency's general survey; hence the feedback only covers the services that are rendered by the sponsor. Two coordinators noted that they do not conduct satisfaction surveys due to a lack of time.

Generally, the coordinators using surveys feel that their utility lies in enabling them to address the negative comments of the clients, assess the impact and effectiveness of SRCP, assess the timeliness of the service by both the sponsor agencies and service providers, identify areas in need of improvement, and assess how SRCP has enhanced the caregiving experience. A few counties do not compile results, either because they do not have the staff resources, they obtain few responses, or they only use the surveys to flag problem situations.

For this reason, because survey findings are confidential (e.g., when the survey addresses all sponsor agency services), or because findings were dispensed with, we were unable to collect survey results from all of the agencies that perform them. The four sets of results that we did obtain showed high levels of satisfaction with service providers and program administration. When asked, survey respondents in large numbers perceived respite to be meeting objectives of relieving caregivers and/or delaying institutionalization.

PART III

PROGRAM CLIENTS AND SERVICES: ANALYSIS OF THE ADMINISTRATIVE DATABASE

OVERVIEW

This section of the report describes the clients of SRCP, their service use, and the impact of key factors—including client characteristics, agency type, policy change, and context—on program and service use. Dimensions of service use include types of services employed, frequency and intensity of care, reasons for service use, duration in program and reasons for termination, and expenditures.

PROGRAM CLIENTS

Overview

The administrative data set provides a clear picture of the respite clientele as predominantly elderly (over 65), female, near-poor (above the poverty level but below the income eligibility threshold of approximately 207% of FPL), having late-onset physical disabilities, and being cared for a relative, most often a child. [See Tables 1a and 1b.] From 1993 to 1999, almost 9 out of 10 respite clients were elderly at the time of admission, with the vast majority of these aged 75 or older.[17] A little more than half had incomes over the poverty level. Almost half were being cared for primarily by a child, with four out of five of these being daughters. Another third were cared for by a spouse, almost equally divided between husbands and wives. However, three-quarters of the clients were female.

Two primary diagnoses were coded for each client, and we then grouped these into five diagnostic categories: Alzheimer's disease/senile dementia (AD/SD),[18] mental illness, developmental disability, later-onset physical disabilities/diseases (as distinguished from developmental disabilities),[19] and a vestigial category of "other," combining those whose diagnosis did not fit into one of the program's diagnosis codes with those coded as "deterioration due to aging." Thirty-four percent of clients were diagnosed with AD/SD. Seventy-one percent of clients had at least one late-onset physical disability, the most common of these being stroke (17.8% of the total), heart disease (16%), arthritis (11%), and diabetes (10%). Only two percent each had a diagnosis of mental illness or a developmental disability, including autism, mental retardation, muscular dystrophy, cerebral palsy, and spina bifada. Fully 16.3% of clients had at least one condition coded as "other."

Since up to two diagnoses could be coded for each client, they could belong in more than one diagnostic category. While most did not fit in more than one category, 13.6% had both a diagnosis of AD/SD and a late-onset physical disability/disease, 8.31% had both a diagnosis of physical disability/disease and "other," and 2.1% had a diagnosis of AD/SD and "other." Other possible combinations of diagnostic categories encompassed less than one percent of the client population each.

We speculated that diagnosis would be associated with other client characteristics [Tables 2a and 2b]. It is not surprising that developmentally disabled care recipients look different from the other clients. They are much younger, of course, and therefore much more likely to be taken care of by a parent (almost always a mother). A large number have a sister as their primary caregiver.

Table 1a. Characteristics of Care Recipients of the Statewide Respite Care Program, 1993-1999

(N=7965)

Care Recipient Characteristics	Percent of Care Recipient Population
Age at entry	
18-39	2.1%
40-64	8.6
65-74	18.4
75-84	39.4
85+	31.6
Diagnosis	
Late-onset physical disability/disease	71.0%
Alzheimer's disease/ senile dementia	34.0
Developmental disability	2.1
Mental illness	2.0
Unspecified condition or deterioration	16.3
Gender	
Male	29.7%
Female	70.4
Income	
Below poverty	44.8%
Above poverty	55.2

They are also more evenly distributed by gender than the others; the gender imbalance at older ages is due largely to differential life expectancy between the sexes. Finally, they are much poorer than the other clients, with 81.9% below the poverty level; again, this is not surprising, given the fact of their lifelong disability.

Also not surprisingly, clients with Alzheimer's disease or a related disorder are most likely to be in the two highest age categories, followed by those in the "other" category and then those with late-onset physical disabilities/diseases. In other respects, the four diagnoses other than developmental disability are associated with fairly similar client profiles.

Table 1b. Relationship of Caregivers to Care Recipients in the Statewide Respite Care Program, 1993-1999

(N=7965)

Caregiver Relationship	Percent of Caregiver Population
Wife	17.7%
Husband	15.1
Parent	2.7
Sibling	4.0
Son	10.0
Daughter	38.7
Other relative	9.4
Friend	1.8
Other	.5

Program Participation

Table 2a. Care Recipient Characteristics by Diagnosis

	Late-Onset Physical Disability/ Disease (N=5654)	Alzheimer's Disease/Senile Dementia (N=2710)	Developmental Disability (N=168)	Mental Illness (N=162)	Other (N=1267)
Age					
18-39	1.2%	.2%	36.1%	.8%	3.0%
40-64	9.0	2.8	21.1	11.2	9.9
65-74	17.8	13.6	7.8	27.2	10.3
75-84	37.5	44.6	7.2	46.4	26.5
85+	34.5	38.83	.61	4.45	0.3
Gender					
Male	30.2%	27.6%	43.7%	25.5%	27.6%
Female	69.8	72.4	56.3	74.5	72.4
Income					
Below poverty	44.9%	41.0%	81.9%	42.8%	45.5%
Above poverty	55.1	59.0	18.0	57.3	54.4

Table 2b. Caregiver Relationship to Care Recipient by Diagnosis

	Late-Onset Physical Disability/ Disease (N=5654)	Alzheimer's Disease/Senile Dementia (N=2710)	Developmental Disability (N=168)	Mental Illness (N=162)	Other (N=1267)
Wife	15.3	14.5	7.0	21.1	11.0
Husband	18.3	18.6	3.9	12.7	12.4
Parent	1.7	.5	55.9	2.1	4.3
Sibling	3.6	2.8	17.1	8.4	5.5
Son	10.2	8.9	3.9	5.6	13.4
Daughter	38.8	42.7	5.4	37.3	40.0
Other relative	9.5	10.3	3.9	9.2	10.1
Friend	2.0	1.2	1.6	2.1	2.9
Other	.6	.4	1.6	1.4	.4

Program participation was measured in two ways: 1) by comparing the allocation of the program budget among the counties to the distribution of program participants among the counties, 2) by comparing program participants to estimates of the low-income disabled adult population.[20] The latter allowed us to compare the county distribution of the low-income adult disabled and the program participants overall, and to compare the proportions of poor/near-poor and elderly/non-elderly among the low-income adult disabled and program participants in each county and overall.[21]

The distribution of program participants among the counties is virtually identical to the allocation of program monies, suggesting that all the counties are doing a good job of spending the dollars they are given.[22] We found that the elderly are greatly overrepresented among the program participants, except in Bergen county. The obvious explanation is that Bergen is the only place where the sponsor agency serves the disabled as its broader mission, and in fact 7.2% of Bergen's clients are developmentally disabled, as opposed to 2.1% of program clients overall.

We also found that the income distribution of the SRCP clients in fifteen of the twenty-one counties is approximately the same as that of the low-income adult disabled for those counties. There were six exceptions. In all of these cases, the program's proportion of poor clients was actually higher than the proportion of poor among the county's low-income adult disabled.[23] In other words, in our estimations, there were no counties in which the poor were underrepresented in SRCP. This is a positive finding, in that a concern in all program implementation is that the neediest of the target population be reached.

What explains the six counties in which the poor were overrepresented? Interestingly, all six are in the top half of the state's counties (ranks 1-11) in terms of median income. Conversely, they are in the bottom half (rank 11-21) in terms of the proportion of low-income adult disabled who are poor. One possible explanation is that the outreach efforts described earlier in this report (e.g., distribution of brochures at health fairs and social service agencies) are particularly good for targeting the poor; and that in counties with smaller eligible poor populations, it is easier to reach a larger percentage of them. It may also be that wealthier counties have a better infrastructure.

SERVICE USE

Overall Service Use

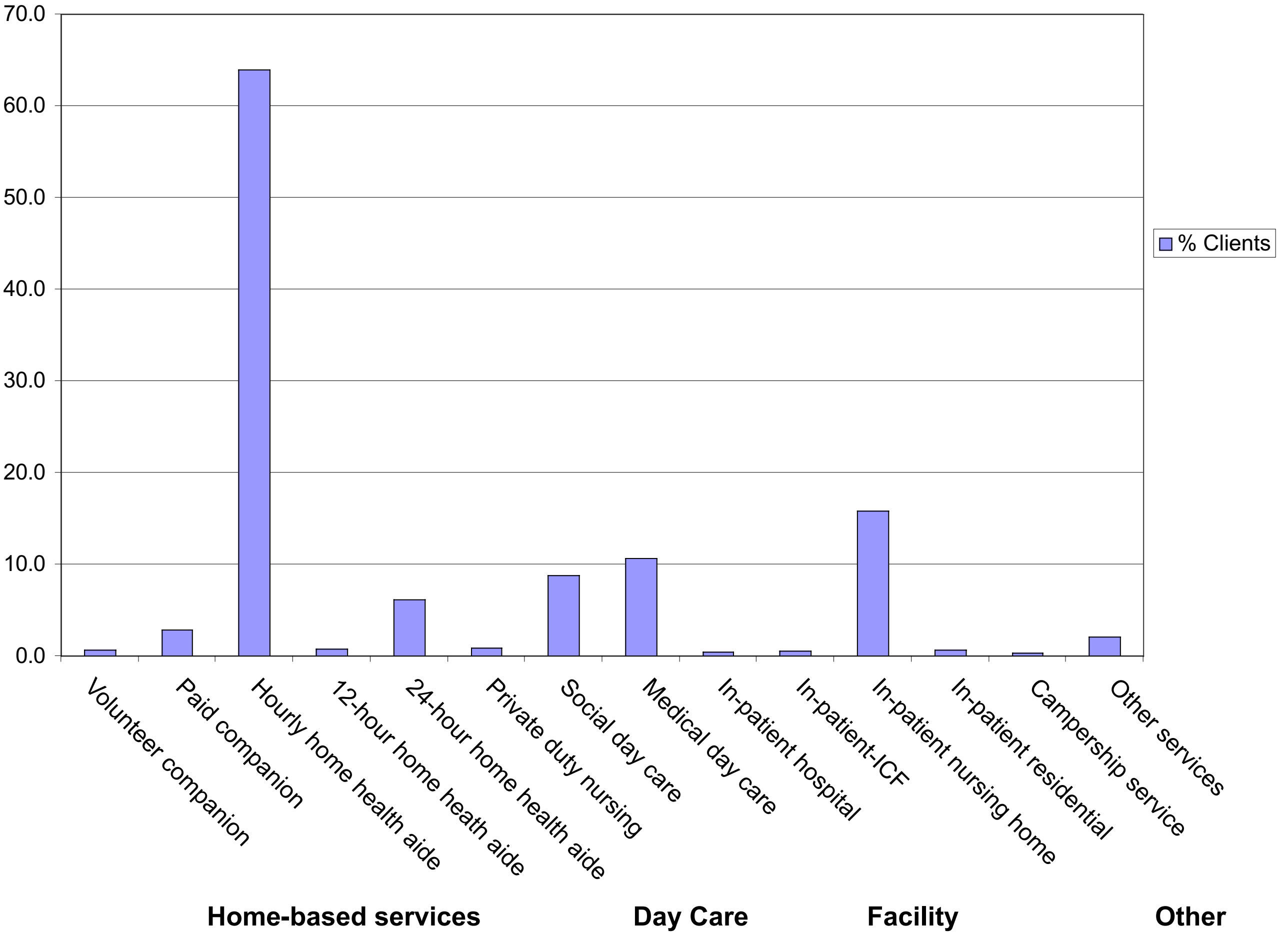
Of the 7,965 program participants, virtually all were formal participants, i.e., they had gone through the process of being accepted into the program. Only 27 (.3%) were not formal participants but only users of emergency services.[24] Seven hundred and eighty-two formal participants (9.8% of the total group) used emergency services at some point; over half of these never used any services other than emergency, despite being accepted into the program. Forty-five percent of those who used emergency services used them only during a single month, and only one-quarter used them in three or more months. Only 390 individuals (4.9%) never used any services at all.[25]

Types of Services Used

Among the individual service types, homemaker/home health aides (HHAs), particularly hourly hhas, were by far the most used [See Figure 1]. Sixty-six percent of program participants used some HHA services; virtually all used hourly services. Six percent of program participants used 24-hour care and less than one percent used 12-hour care.

A distant second to homemaker/home health aide services was nursing home care, used by 15.8% of participants. Medical day care was employed by 10.6% of participants and social day services by 8.8%. All other services were used by small numbers of participants.

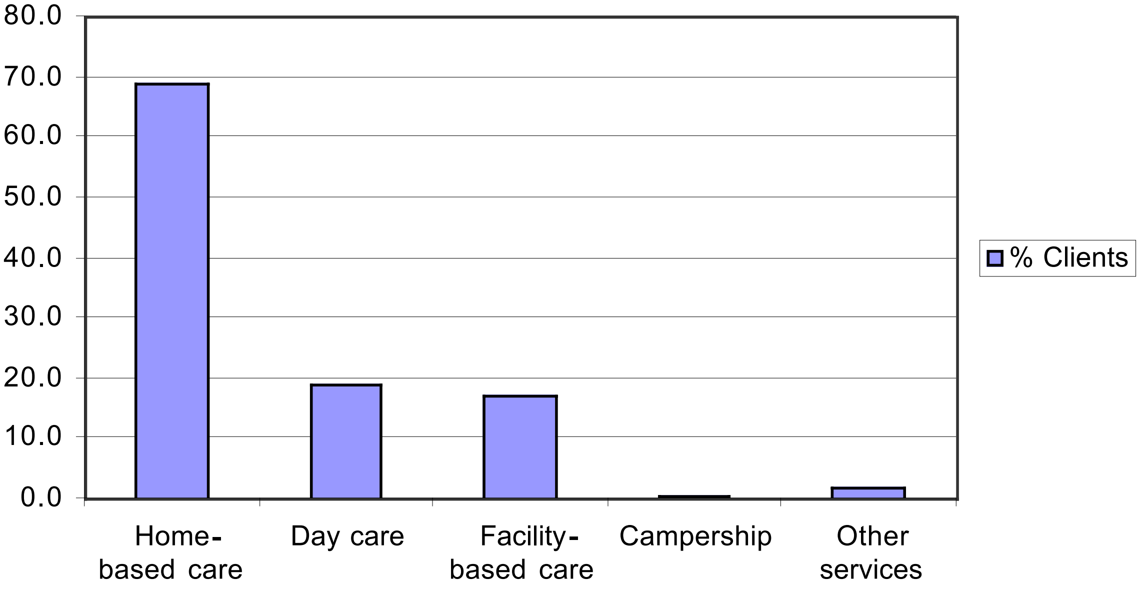
Figure 1. Percentage of Care Recipients Receiving Service by Type Received (N=7965)



SRCP services can be divided into home-based (volunteer companion, paid companion, homemaker, and private duty nursing); community-based (medical day care and social day care); and facility-based (nursing home, intermediate care facility, residential health care facility and hospital). Camperships, while they provide overnight residences, differ greatly from other facilities. They are not institutions, but literally camps, whose purpose is to provide recreation and social opportunities for younger disabled individuals. We have therefore kept them separate.

Looking at the services by these groupings [Figure 2], we found the home-based services to be by far the most common. Sixty-eight percent of participants had used one of these forms of respite. However, community-based care and facility-based care served a significant portion of program participants as well - 18.9% and 17.1% respectively.

Figure 2. Percentage of Clients Receiving Services by Category of Service Received (N=7965)



Service Clustering

From 1993 to 1999, 78.7% of SRCP clients used only one type of service. Virtually all (97.4%) used from zero to two, and the maximum number of service types used was six.

Those using the most popular forms of care—hourly homemaker/home health aide, social day care, medical day care, and nursing home care—and those using hospital care were more likely to use only this one service than to use it in conjunction with another. All other service types (companions, private duty nursing, ICFs, residential health care facilities, camperships, and others) were more likely to be used together with another service than to be used alone. Hourly homemaker/home health aide was, not surprisingly, the service most commonly used in conjuction with all services other than campership. A non-standard or “other” service was the service type most commonly used together with camperships, and 24-hour HHA was the service type most commonly used together with hourly homemaker/home health aide. In fact, about one-third of those using two services were using two variants of homemaker/home health aide (e.g., hourly and 12-hour or 24-hour).

Frequency of Service Use and Intensity

We calculated frequency and intensity of service use for those services that were most commonly used. Frequency was defined as months in which the service was used as a percentage of total months in the program, i.e., how often an individual used each service. Intensity was the average number of units of service employed in each month of use.[26]

Average frequency of homemaker use was .44. In other words, the average user of homemaker services used them 44% of the months in which they were in the program. However, half of the users of HHAs used them 33% of the months s/he was in the program or less, suggesting a number of higher frequency users pulling up the average. We would in fact expect some individuals to use homemaker services for respite on a regular basis, and others to use it for specific isolated purposes. On average, users of homemaker services received 29.2 hours of services per month in which services were used. However, half of homemakers had a service intensity of 16.8 hours or less per month of use, again pointing to some high-intensity users.

Mean frequency of social day care use and medical day care use were both .76. This was not surprising, as we would expect day care to be used on a regular basis to provide caregiver respite and not to be a likely choice for emergencies. In those months in which the service was used, clients averaged 6 sessions of medical day care and 7.6 of social day care. This difference likely reflects the higher per unit cost of medical day care. Given some coordinator comments that they send needier care recipients to medical day care, however, it suggests that needier clients, while getting more skilled care, are getting less of it.

Mean frequency of nursing facility use was a surprising .55. However, half of the clients staying in nursing facilities used them only a quarter of the months they were in the program or less, suggesting both that most clients who use nursing homes do so sporadically and that there are a number of individuals who use them in a more concentrated fashion. Mean intensity was 9.7 days of residence for each month in which the service was used, and the median was 9.0.

EXPENDITURES

Service Use Rates

The cost of services is highly variable. Among the home-based services, service costs approximately double as you move from one skill level to the next. Paid companions are of course the least expensive of the in-home services, ranging from $6-$10/hour, with a mode of $7. Hourly homemaker/home health aides have a large range — $2.50 to $24/hour - but more than half of these service records show a reimbursement rate of $14/hour.[27] Private duty-nursing costs $20-$35/hour. "Volume" purchase of homemaker services, particularly 24-hour care, is highly economical. 12-hour homemakers charge $75-$100, and 24-hour homemakers cost from $100-$125. However, these long visits are not the way in which clients generally use homemaker/home health aide services.

A number of coordinators noted that day care services are an efficient purchase, and the data bear this out. Social day care services are considerably cheaper than medical, ranging from $10 (for a non-standard social day care for people with developmental disabilities) to $33.50 for a session; the bulk of these were charged at $30. Medical day care ranges from $37 to $68.96, with most costing between $50 and $60.

Table 3. Reason for Service by Type of Service (N=111,361)

Service Type	Reason for Service			
	Caregiver Illness	Personal Time for Caregiver	Vaction or Travel	All Other Reasons
Volunteer	3.1%	95.9%	.1%	.8%
Paid companion	.9	97.4	1.4	.3
Hourly home health aide	3.8	94.9	.6	.6
12-hour home health aide	26.8	62.5	8.9	1.8
24-hour home health aide*	22.0	32.2	44.2	1.4
Private duty nursing**	6.3	84.0	8.6	.8
Social day Care	1.7	97.6	0	.7
Medical day care*	1.0	98.4	.1	.4
In-patient hospital	4.3	20.3	73.9	1.4
In-patient ICF	3.5	33.7	62.3	.5
In-patient nursing home**	20.3	20.6	58.2	.7
In-patient residential health care facility	10.2	59.3	27.8	2.8
Campership	0	41.6	58.4	0
All other services	4.0	80.7	15.3	0

*0.1% missing

**0.2% missing

Facility-based care is the most variable in cost. A day in a rehabilitation hospital ranges from $125 to $195, with the bulk between $130 and $150. An intermediate care facilty (ICF) day ranges from $113.50 to $211, and rates are pretty evenly distributed within this range. Nursing home days range from $75 to $196, with a median of $132. Residential health care facilities are far cheaper, costing from $32 to $60. Finally, camperships have a broad range—from $12.50 to $75, and are fairly evenly distributed from $18 up.

Cost-share

Program participants whose incomes are below the poverty line pay no cost-share at all. For those above the poverty line, there are five cost-share categories, starting with 5% of service costs and increasing at 5% increments to a maximum of 25%. Almost half of the program clients from 1993 to 1999 paid no cost-share at all, and another third paid only 5 or 10%. Only 4.5% of clients paid the highest cost-share amount of 25%.[28]

Annual Expenditures[29]

In any given year, most clients did not exceed the service cap (ranging from 92.9% in 1998 to 97.5% in 1993). Each year, almost 40% of clients spent between $2,000 and $3,000, about a quarter spent $1,000 to $2,000, and one-third or more spent less than $1,000. Only a small number of individuals spent over $4,000 in a given year; from 1995 to 1999, one or two each year spent over $6,000.

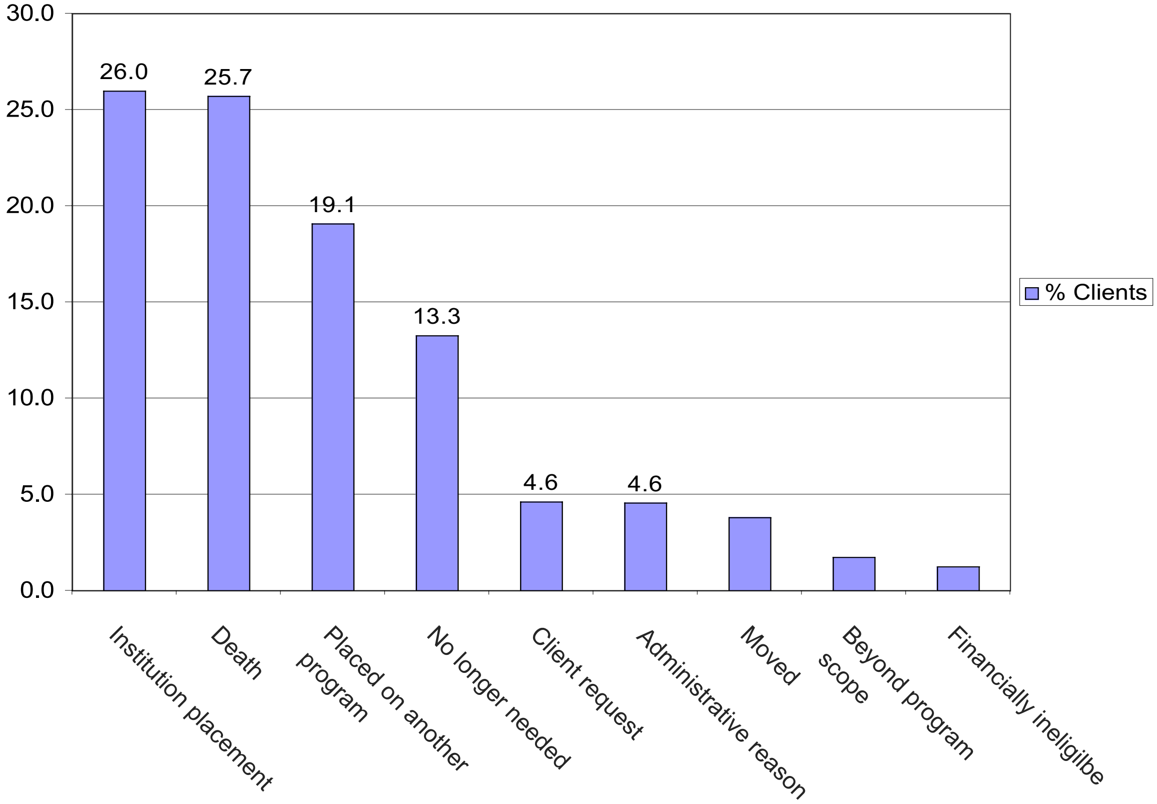
Reasons for Service Use

Service records provide four pre-coded categories of reasons why services were used—caregiver illness, personal time for the caregiver, vacation or travel, and all other reasons. Interpretation of this data should be cautious, as it is not clear that all coordinators ascertain a reason each time a service is used. Some may consistently re-record the reason offered at the time of program entry. On the whole then, the data probably describe a combination of initial reasons for program entry and reasons for use of care in a given moment.

Nine out of ten times, the reason recorded for service use was caregiver personal time. Less than 1% of reasons fell into the “all other reasons” category, and the remaining 9% of reasons were divided almost evenly between caregiver illness and caregiver vacation or travel.

Not surprisingly, reason for service use corresponded closely to the type of service employed, with home and community-based care almost always used to provide the caregiver with personal time [Table 3]. Facility-based care was used primarily to facilitate caregiver vacation or travel, but was also used for personal time in a significant percentage of the cases. Only for one type of facility—residential health care facilities—was caregiver personal time the dominant reason for care.

Figure 3: Percentage of Terminations by Reason for Termination (N=6338)



DURATION IN PROGRAM AND TERMINATION

Duration in Program

Duration in program was calculated for the 5426 program participants who had both acceptance dates and termination dates in their 1993-1999 records.[30] The vast majority of these individuals (95.9%) had only one complete stay in the program in that time period. 3.6% had two stays, and 24 individuals had three stays. First stays averaged 382 days, with a median of 231, suggesting a number of much longer stays. Each consecutive stay was increasingly shorter, with a mean of 296 days for the second stay and 257 days for the third stay. Because so few program participants had more than one stay, total duration in program (the sum of all three) averaged only 12 days more than duration in program for the first stay (i.e. 394 days), and was therefore the operational measure of duration that we used for most analyses. Surprisingly, only a small percentage of the variation in length of stay was explained by age at entrance into program.

Termination

Reasons for termination are recorded in the database in nine pre-coded categories. These are: care recipient has died, care recipient has moved, care recipient has been placed in an institution, client has requested termination, care is no longer needed, client has moved beyond the scope of the program, client has become financially ineligible, client has been placed on another program, and an administrative reason.[31]

In the study period, 6,038 of the program participants had termination records. A number had more than one because they left the program, were readmitted and terminated again. As a result, there were a total of 6,338 termination records. Death and institutional placement together made up about half of the reasons for termination—approximately one-quarter each. [See Figure 3.] Placement in another program and the general category of program no longer being needed together accounted for one-third of terminations.

WAIT LIST

Counties have different policies and experiences with regards to maintaining a wait-list, but all wait-listed individuals are in the administrative database. From 1993 to 1999, the size of the wait-list statewide varied moderately, ranging from 712 to 983. Half of those wait-listed during this time never entered the program. Of those remaining, 45% were on the list three months or less before being accepted, and the vast majority (93%) were on the list less than a year. Eighteen people were on the list more than three years. However, program staff believe that those with long waiting list stays were usually receiving other services.

Wait-listed clients look very much like program participants in terms of sex, diagnoses, and caregivers. The only notable difference is that a larger number of those in the wait-listed group than of program participants were in the oldest-old category (37.9% vs. 31.6%).

PATTERNS OF SERVICE USE

This project set out not only to describe clients and services, but to understand factors associated with specific patterns of program and service use. These factors include client characteristics, agency type, policy type, and contextual change and difference. We focused on those factors and relationships which previous literature, coordinator interviews or Advisory Committee input suggested were important.

Client Characteristics

Differences by Diagnosis

Clients show significant differences in service use by diagnosis [Table 4]. Clients with Alzheimer's disease/senile dementia or mental illness were far less reliant on home care than the client population overall and far more reliant on day care; day care was used by approximately one-third of these individuals, but less than one-fifth of the total group. Moreover, clients with Alzheimer's disease and the developmentally disabled population were more likely to use institutional care than those outside these diagnostic groups.

Clients also show interesting differences by diagnosis in the use of individual service types. Most notably, developmentally disabled clients were more likely than others to use a number of the less popular services, including private-duty nursing, 24-hour homemaker/home health aides, intermediate care facilities, and camperships. Developmentally disabled participants were also more likely to use the program's county-specific services.

Having a diagnosis from more than one category made a difference in service use patterns as well. Interestingly, those with AD/SD and a late-onset physical disability/disease were more likely than those with only AD/SD to use hourly home health aides but less likely to do so than all other clients. Conversely, they were less likely than those with AD/SD only to use social day care and more likely than all others to do so. The same held true for medical day care. Potentially, then, the condition of AD/SD creates a push to use day care, but the presence of a (late-onset) physical disability/disease is a disincentive to do so.

Duration in program was also strongly associated with diagnosis, in ways that were logical. Average total duration was 349 days for those with a diagnosis of Alzheimer's disease/senile dementia (reflecting the progression of this condition and its caregiving challenges), 405 days for those with a late-onset physical disability/disease, 506 days for individuals with a mental illness, and 840 days for those with a developmental disability (presumably reflecting in part their younger age at entry). For all four of these diagnostic categories, the differences in duration in program between those with and without the diagnosis were statistically significant.

Reasons for termination (as a percentage of total terminations) are strikingly associated with diagnosis. This is particularly true of termination due to death. Those with late-onset physical disabilities were much more likely to have terminated due to death than those without this diagnosis. Conversely, clients with AD/SD, mental illness, or a developmental disability were much less likely to have terminated due to death than others. Another notable difference is the proportion of terminations due to institutional placement; this percentage was much higher for those with AD/SD than without (36.7% vs. 20.5%), presumably reflecting the progression of the condition, and much lower for those with a late-onset physical disability/disease than without (22.3% vs. 35.0%). Other differences were notable as well. Those with mental illness were more likely than others to have terminated due to client request, and less likely to have terminated because of being placed on another program. The terminations of those with developmental disabilities were more likely to be attributed to the service no longer being needed.[32]

Caregiver Relationship and Termination

Previous research has shown a correlation between caregiver type and likelihood of admittance to a nursing home.[33] Our data demonstrated statistically differences in the expected direction in the reasons for termination of clients cared for by spouses and others; these differences were, however, extremely small.

A related hypothesis was that dyads with spouse caregivers would stay in the program longer than others. However, average duration in program was not statistically different for the two groups.

Table 4. Service Use by Diagnosis

Service	Care Recipient Diagnosis				
	Alzheimer's Disease/ Senile Dementia (N=2710)	Mental Illness (N=162)	Developmental Disability (N=168)	Late-Onset Physical Disablity (N=5654)	All Clients** (N=7965)
Any in-home care	56.2 %*	51.2 %*	67.9%	73.9%*	74.5%
Volunteer companion	.7	.6	.6	.8*	.7
Paid companion	2.7	3.7	6.0*	2.7	2.9
Any home health aide	54.4	48.8	66.1	71.9*	66.3
Hourly	52.1	45.7	59.5	68.7*	63.9
12-Hour	.7	0	1.8	.7	.7
24-Hour	5.1*	5.6	13.7*	6.7*	6.1
Private-duty nursing	0.5*	.6	4.2*	1.0	.9
Any day care	31.3*	37.7*	15.5	13.7*	18.9
Social day	14.9	21.0	10.1	5.5	8.8
Medical day	17.4*	17.9*	5.4*	8.5*	10.6
Any institutional care	21.6*	19.8	27.4*	16.4*	17.1
Nursing home	20.3*	17.9	16.7	15.2*	15.8
ICF	.4	.6	10.1*	.4	.6
RHCF	.91	.2	0	.5*	.7
Hospital	.3	.6	2.4*	.4	.5
Campership	.1*	0	7.7*	.1*	.3
Other	1.7	4.3	10.1*	1.9*	2.1

* An asterisk denotes a statistically significant difference between the percentage of individuals in this diagnostic category using the service and the percentage of individuals outside this diagnostic category using the service.

** The category of "Other diagnosis or deterioration due to aging" is not analyzed separately because it is a vestigal category.

Income, Duration in Program, and Termination

We hypothesized that income would be related to duration in program and reasons for termination. Based on existing literature on health services and income and race (which is correlated with both income and attitudes towards caregiving), we expected that length-of-stay would be longer and termination for institutionalization less common for those below the poverty level.[34] While the differences in termination were in the right direction and statistically significant, they were extremely small. The difference in duration was not significant.

Agency Type

A major consideration for program implementation is whether the nature of the local sponsor agency affects how the program is run. In particular, we wondered whether provider agencies were more likely to design service plans utilizing the services they provide, either due to conflict-of-interest, bias, or the ease of accessing their own services. We found that, looking at all years of the study, the clients of home health agencies and the clients of government and non-profit agencies were for all intents and purposes equally likely to use homemaker services, and employed them with the same frequency and intensity. However, this was not as true in the context of the current home health aide shortage, as will be discussed in more depth later. The fact that this divergence occurs within the context of the home health aide shortage suggests that it is due to the difficulty for agencies other than home health agencies of getting aides, not to a bias towards using aides on the part of home health agencies.[35]

Another dimension of agency difference is the type of clientele served through the agency's larger mission. As noted before, this clearly has an impact on program implementation, as demonstrated in the case of Bergen County. Bergen is the only county in which the sponsor agency's larger mission is specifically to serve the disabled, and it is the county which has the largest percentage of developmentally disabled clients, and the only county in which the younger disabled are not underrepresented.

Policy Change

Interviews revealed two major policy changes during the study period that would be expected to cause visible changes in program clients: expansion in the program budget in July of 1998 and July of 1999, and a change in the rules of financial eligibility in June of 1998.

Program Expansion

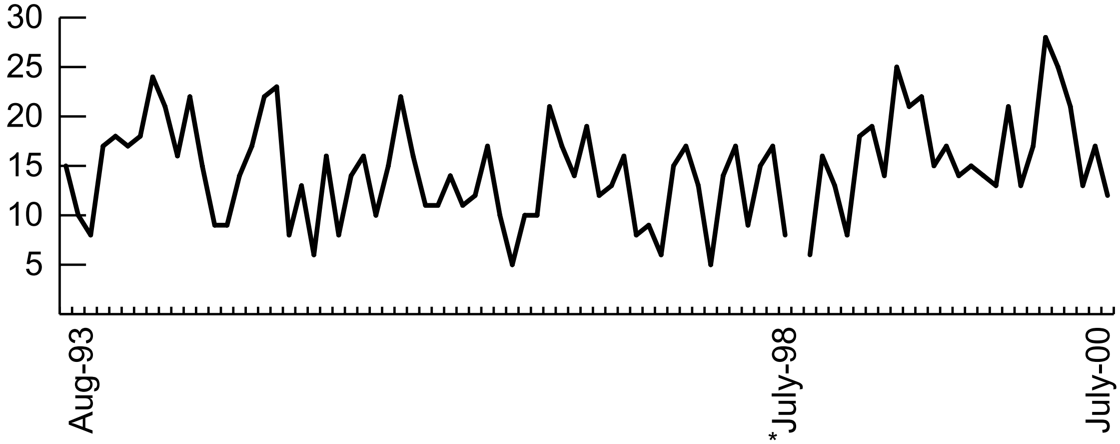
In 1998 and then again 1999, the SRCP budget was expanded significantly, with the new budget to take effect in July at the beginning of the fiscal year. In 1999, however, the new monies

Table 5. Impact of Budget Expansions

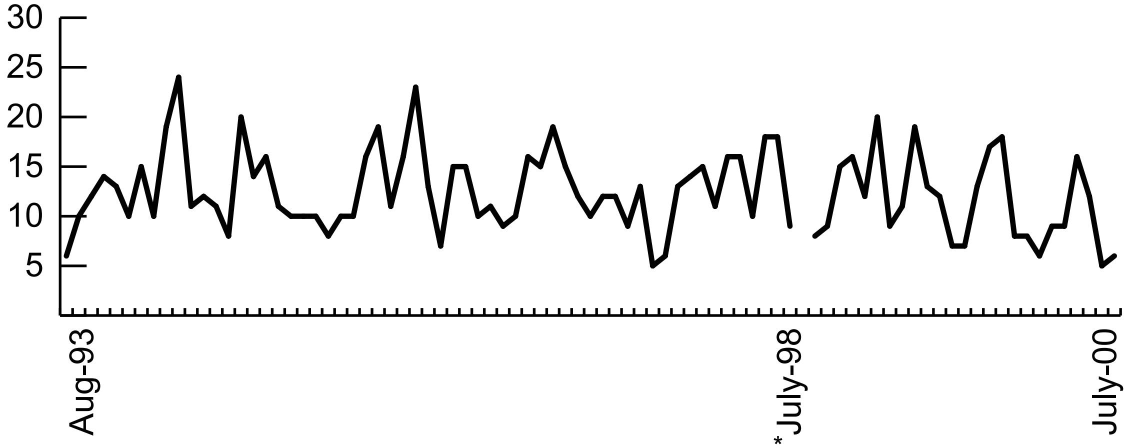
Six-Month Period	Number of New Program Participants
1997: First six months	483
1997: Second six months	458
1998: First six months	481
1998: Second six months	577
1999: First six months	551
1999: Second six months	579

Figure 4. New Entrants to Program by Caregiver Relationship, August 1993–July 2000

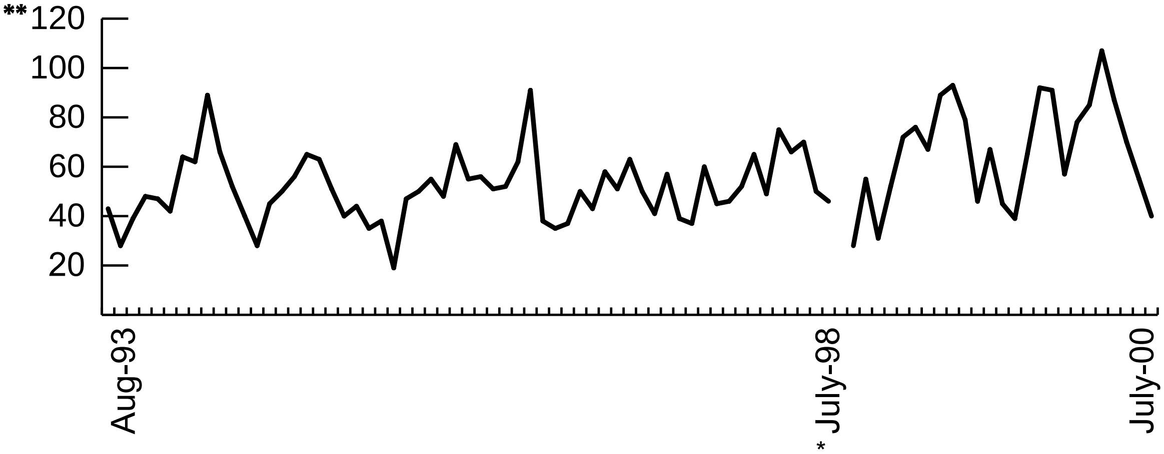
a. Number of Caregiver Entrants (Wives), August 1993–2000



b. Number of Caregiver Entrants (Husbands), August 1993–2000



c. Number of Caregiver Entrants (Other Caregivers), August 1993–2000



*Program change implemented June 1998

**Note scale change to a maximum of 120

were promised but not dispensed until November. DHSS staff expected that, logically, coordinators would be unwilling to enroll new participants without the money in hand—a sentiment also expressed by some coordinators. The data bear this out [See Table 5] showing only a small difference in number of new program participants. However, the data do show a rapid response on the part of coordinators to the new monies that were dispensed promptly in 1998. From the first half of 1998 to the second half, the number of new entrants jumped from 481 to 577. This does not seem to be attributable to a seasonal effect, as no similar jump occurred in 1997 or 1999.

Change in Financial Eligibility

As described earlier, prior to June of 1998, financial eligibility for all applicants was based on the care recipient's income alone. In June of 1998, financial eligibility for couples was changed to the couples' income. The change was motivated by staff concern that the previous system disadvantaged caregiving wives, since in many cases they would have lower incomes than their husbands; while a couple's per person income might be equal to or less than that of a single individual, the husband's income would make them ineligible. By basing income eligiblity for couples on their combined income and establishing an eligibility threshold double that of singles, program administrators hoped to facilitate program use by client dyads with caregiving wives.

To illustrate, imagine a couple Martha and John. John is homebound and Martha is his caregiver. The retirement income of each (pensions, Social Security) is based on their lifetime earnings. Martha was a housewife and mother, or perhaps worked outside the home, but made less than her husband (as women still earn less than men on average). Her current monthly income is $1,200. Her husband, John, has a monthly income of $1,700. Under the old rules, eligibility determination would be based on John's income, which exceeds the individual limit of $1,590. Under the new rules, the couple's combined income of $2,900 would be the basis for assessment; as this combined income is less than $3,3180 (the limit for couples), Martha and John would now be eligible.

While not an objective of the eligiblity change, we might also expect the new policy to reduce the numbers of husband caregivers coming into the program, given the likely prevalence of wife care recipients with low incomes. For example, imagine another couple, Laura and Jim. Laura has become ill, and Jim is her caregiver. Laura's monthly income of $1,400 previously made her eligible for the program. However, Jim's income is $2,000. Under the new rules, their combined income of $3,400 makes them no longer eligible. While couples already on the program were not removed under these conditions, the new Jims and Lauras would not be able to enroll. What is the net result?

Figures 4a and 4b demonstrate that the number of wives entering the program increased after June of 1998 and the number of husbands decreased. However, at the same time as the change in eligibility policy, the overall budget was expanding and so was the number of participants in general. To show an effect of the change in eligibility criteria, therefore, we would need to show that the number of wife caregivers was growing faster than that of non-spouse participants (who would be affected only by the budget expansion, not the change in eligibility determination). In fact, we find the opposite. Comparing the eighteen months before and after the simultaneous policy change and budget expansion, we find that the number of new non-spouse caregivers grew at a rate of 1.41; i.e., for every program entrant prior to July 1, 1998, there were 1.41 after that date. (That growth is visually represented in Figure 4c). The number of new wife caregivers grew only at a rate of 1.32. The number of new husbands caregivers declined, as reflected in a "growth rate" of .89.

What explains why the policy change seems to have adversely affected client dyads with husband caregivers while not helping client dyads with wife caregivers? One unlikely explanation is that the needs of the latter population are already being met. A more likely explanation is that this outcome reflects the maintenance of the asset limit at $40,000. In fact, the asset limitation now applies to the couple's combined assets; two people are likely to have more assets than one. It seems probable, therefore, that some couples who might meet the new income threshold are nonetheless ineligible because of the asset threshold.

Change in Context

In their interviews, program staff identified a number of contextual factors that were relevant to program functioning. We did not expect most to lead to demonstrable changes in the client profile or service use patterns. One that we thought might was the current shortage of home health aides, which coordinators reported as a major difficulty for them. As it is known that the labor market for home health aides (and similar low-skilled, low-wage jobs) is quite sensitive to the unemployment rate, we used quarterly unemployment as a proxy for home health aide availability (higher unemployment meaning greater availability) and tested its relationship to the percent of client using home health aides. While we did not see much of a decline in the percentage of clients using home health aides from the times of highest unemployment to lowest unemployment overall, a different picture emerged when we looked separately at the trends for counties in which the sponsor was a home health agency and in which it was a government or non-profit agency. While counties with a home health agency sponsor showed no drop, the others showed a drop of close to seven percentage points.

PART IV

CONCLUSIONS

INTRODUCTION

From a staff perspective at both the local and state levels, the SRCP is being implemented well and performing well. The program receives high marks on dimensions of program procedures, intra-program relationships, external relationships, and benefits to the client. Analysis of qualitative and quantitative data supports many of these perspectives and even reveals additional strengths, such as effective outreach to the poor, that were not mentioned by staff. Staff interviews also make reference to some areas for further development or consideration, such as the program's relationship to the younger disabled. Again, related content of the interviews and quantitative data support many of these insights as well and raise additional issues.

MISSION AND APPROACH

While coordinators evidence some diversity of views as to who is the program's primary client, there is a clear understanding of program goals and a clear commitment to both caregiver and care recipient clients. This is reflected in a flexible, creative, client-driven approach to program implementation, evidenced not only in DHSS staff and coordinator comments, but in their approaches to specific activities, such as service planning, use of cost-share funds, and clinical assessments. The program's policy history also demonstrates a commitment to continually enhancing program performance. Coordinators play an important case management role for their clients. This lends support to the utility of the current proposal to create universal eligibility with cost-share going up to 100% (although the decision must be made on a number of factors); even clients paying all of their own program costs would likely benefit from the service coordination provided by the county coordinators. Some specific questions of mission definition are raised by the expectations and needs of clients who may require more than respite, the development of new state programs targeting similar populations, and—as will be further discussed—the program's current emphasis on the elderly.

PARTICIPATION BY THE TARGET POPULATION

All counties are effectively bringing in clients, as reflected in a comparison of budget allocation to client distribution. Moreover, the needier segments of the target population—as measured by income—are well-represented among program clientele throughout the state, and even "overrepresented" in some counties. However, the younger disabled are underrepresented in all counties but one, and staff comments suggest that the mentally ill are underrepresented as well.

The 1998 change in financial eligibility criteria appears not to have had the desired effect of increasing the participation of dyads with caregiver wives. The most likely reason is the extension of the $40,000 asset limitation to couples.

BUDGET

As with most government programs, staff perceive limitations on their work resulting from budget restrictions. In particular, they see the budget as limiting: per client expenditures, needed staffing, outreach activity, and their ability to serve all those who meet the eligibility requirements. Staff also note a serious challenge in the difficulty of obtaining services at the program's low reimbursement rates.

Assessing the claim of unmet need among program eligibles is difficult, as coordinators generally reduce outreach when funds are short or a waiting list is developing; the size and turnover rate of the waiting list could otherwise be an indicator of such need. Interpreting the size and turnover of the waiting list is further complicated by not knowing how many of those who never enter the program or who are on the waiting list for a long time have been accepted into other programs. However, the 1998 budget increase did immediately lead to a dramatic growth in program participants, lending support to the belief that there was unmet need among the eligible population. The impact of the 1999 expansion was restricted in the short term because of the late disbursement of funds, and an analysis of year 2000 data will be required in order to assess its effect.

A major concern for some staff is the $3,000 cost cap. The fact that on average users of medical day care used fewer units of care in a month than did users of social day care (and both used day care the same number of months out of their stay in the program) suggests that, due to the higher costs of medical day and the restrictions of the cost cap, clients were forced to accept a lower quantity of care in order to get a higher skill level. Use of medical day care may be the result of scarcity of social day services or the need levels of the care recipients. Interviewee comments and the relationship of diagnosis to medical day care use suggest that it is at least in part the latter. If needier care recipients are forced to use less care in order get the skill level they need, this is a concern.

STATEWIDE IMPLEMENTATION

Program operations and internal relations at a statewide level receive high marks from both DHSS staff and county coordinators. Many perceive a need for more program staff at both the state and local levels. Nonetheless, they are pleased with program implementation. Communication, organization, commitment, and oversight are keys to this perceived effectiveness, and are valued at all levels of the program.

LOCAL IMPLEMENTATION

Our data suggest a number of local conditions that affect program implementation: the local home and community-based care market, the availability of free services, population density (which is associated with the market), county size (which is perceived to affect program-client relations, outreach, demand, and the market), and county income distribution (affecting outreach challenges and success in reaching the poor).

However, our data also suggest that some aspects of local implementation are less a function of different local circumstances than of sponsor agency characteristics. The use of homemaker/home health aides—the most popular service type—seems to be affected by sponsor agency type only within the context of the current home health aide shortage. Program implementation is also affected by the client group of the larger sponsor agency, and is perceived by staff to be shaped by differences between private and public sponsors, sponsor resources, and staff allocations.

Finally, local implementation seems to be shaped by the ideas and perspectives of the individual county coordinator, influenced in part by experience and training. Because of the creativity and client-focus of the staff, the counties do function as “laboratories” for program implementation. On the other hand, our interviews suggest some concern over the great diversity in implementation, a concern which is supported by the impact of sponsor agency type described above and by the normal difficulties that face county coordinators. One way to take advantage of the experimentation of different counties and to simultaneously promote universal adoption of best practices is through intra-program contact and communication. The program’s general meetings are such a mechanism. Given the challenges of the geographic dispersion of the coordinators, other mechanisms (such as ways of encouraging electronic communications) should be considered as well, with an explicit focus on best-practice learning.

PROGRAM FLEXIBILITY AND CONVENIENCE

Staff cite a number of dimensions of program flexibility and convenience as strengths. These include the ease of the application process and eligibility determination, the diversity of services, flexibility in deviation from service plans, the ease of obtaining cost cap extensions, and discretionary use of cost-share funds.

SERVICE USE AND DIVERSITY

Hourly home health aides are by far the most used program service. However, the data also strongly support the importance of service diversity. Significant populations also use day care and institutional care, particularly nursing homes. More striking, service use varies in key ways by diagnosis, demonstrating the importance of service variety for meeting the needs of a diverse population. Frequency and intensity of service use for the most popular types of care also demonstrate diversity in the way services are used. Moreover, while most program participants employ only one service type, a number of care recipients, especially those who use the less popular forms of care, use more than one. Finally, a number of staff note advantages and disadvantages of each form of care, and some stress that care recipients with different levels and types of need require different services.

ALZHEIMER’S DISEASE / SENILE DEMENTIA

Approximately one-third of the program’s participants belonged in the diagnostic category of AD/SD. Almost one-third of these clients also had what we termed a “late-onset physical disability/disease,” such as a heart condition.

Types of services used, duration in program, and reasons for termination varied by diagnosis. Clients with Alzheimer’s disease/senile dementia were far less reliant on home care than the client population overall and far more reliant on day care. (The addition of a diagnosis of “late-onset physical disability/disease” somewhat mitigated both differences.) AD/SD clients were also more likely to use institutional care.

Average total duration for those with a diagnosis of Alzheimer’s disease/senile dementia was shorter than for those without. Clients with AD/SD were less likely to have terminated due to death and more likely to have terminated due to institutional placement than others.

MARKET RESTRICTIONS

Like most community-based long-term care programs, SRCP faces some challenges stemming from inadequacies in the private market, particularly in certain communities. These are compounded by the program's low reimbursement rates and, for institutional care, the care recipients' limited stays. The current home health aide shortage is making the sponsors' jobs more difficult, and counties with government or non-profit sponsors show a drop in the percentage of clients using home health aides.

BENEFITS TO CLIENTS

Nationwide, late entry into respite programs is a major concern, and staff believe it to be a reality for SRCP as well. The average duration in the program of a little over one year, and the fact that half of terminations are due to death or institutionalization suggest that this may in fact be the case. While outreach is one response to this problem, that needs to be balanced—as staff point out—with the ethical mandate not to raise false expectations.

Staff described important benefits to care recipients when they do come to the program (and the satisfaction surveys to which we were privy support this belief). Two perceived benefits mirror the program's primary goals: caregiver relief and delayed institutionalization. Staff noted other benefits as well, including an improvement in the quality of life of the care recipient. Interestingly, several coordinators noted that care recipients need respite from caregivers too. The flexibility for which SRCP is partly known is seen as an important element in achieving these benefits for care recipients.

Staff perceptions of program benefits were supported by the limited client satisfaction survey data available. Clients gave high marks to SRCP and the quality of services they received under it, and saw it as both helping caregivers and delaying institutionalization.

APPENDIX I

INTERVIEW PROTOCOLS

DHSS STAFF INTERVIEW

A. Involvement with Program: Just to help understand your perspective.

1. How long have you been with the program?
2. What are the positions you've held in the program?
3. Before coming to work with the program, had you worked in state government? Had you worked in government or outside on long-term care issues?

B. I'm going to ask some questions about program mission and philosophy.

1. I know from written descriptions of the program that you consider the client to be both the caregiver and the care recipient and that the program's goals are: 1) to relieve caregiver stress and 2) to delay institutionalization? Is that correct? In that order?
2. Is there anything additional you want to tell me about the program philosophy?
3. Do you believe that philosophy is shared by your constituents—in government? The clients themselves?
4. How is the philosophy manifested in the program design?
5. Has the philosophy changed over time?

C. I'm going to ask some questions about the way the program works.

1. Is the program still essentially as described in this original document? (camperships? budget?)
2. How do you choose county coordinators? How often? Is there much competition for these contracts? Is there much turnover? Crystal found in 1992 that half of the sponsors were home care agencies, and the other half were social service organizations, agencies for the aging, and hospitals? Is that still the composition?
3. Could you explain to me the division of responsibilities between the Wellness and Family Support Program Office in DHSS and the county coordinators' duties?
4. I know that financial determinations are done at the beginning of the new calendar year and clinical reassessments are done every 6 months? When? I 've seen the clinical assessment form? Who carries out the clinical assessment? Where? How is reassessment done? How is financial eligibility determined and redetermined?
5. How do the county coordinators go about creating a service plan for a client? What is their decision-making process? How do they involve the clients in that process?

6. How often do you meet with staff individually or as a group? What are the functions of these meetings? What are your other mechanisms for communicating with the county coordinators?
7. How do the county coordinators choose their service vendors? How often? Is there much competition for these contracts? Is there much turnover?
8. How do you maintain accountability within the program - you over county coordinators and coordinators over vendors?
9. I know you've had a change in the MIS system? Could you describe?
10. What do you do to advertise the program? How does this respond to availability of slots?
11. How do you go about the process of waiving cost cap or cost-share? Letting in Medicaid eligibles?
12. Is the caregiver training program in operation? How long has it been?

D. Now I'm going to ask you some more evaluative questions about your program.

Overall

1. Thinking about all the aspects of the program we've just discussed and others, what do you think is working well in your program? What are the advantages of your program as it is currently designed? What are the benefits of the program to caregivers and care recipients?
2. What are areas that need improvement? What are disadvantages of the program as currently designed?
3. What are external obstacles to your work?

Clients and Services

4. Do you have a sense of when most clients come to the program? At what stage of dealing with the disease or disability? What do you base this impression on? What do you think is the impact for the clients and the program?
5. Do you have a sense of what types of services are working best for clients? What do you base this impression on? What services do you think that clients need that they are not currently receiving?

Relationships/Operations

6. What are your impressions of program-client relationships, both for caregiver clients and care recipient clients? How well are they working? What are advantages and disadvantages of how the program is structured in this regard? You told me that some counties are doing client satisfaction surveys. They're not required? Are many doing them? What do they show?
7. What are your impressions of program-provider relationships? How well are they working? What are advantages and disadvantages of how the program is structured in this regard?
8. Steve talked about a conflict of interest in having coordinators conduct clinical assessments when they might also be service providers. Is this still a possibility? Is it a concern for you?
9. What is your impression of internal program operations, i.e. between DHSS and county coordinators? How well is it working? What are advantage s and disadvantages of how the program is structured in this regard

Changes

10. What do you think have been the most important changes in the program over time? [Ask to describe and to comment on implications of these changes.]
11. What changes in the state and national policy context do you think have had an effect on the program? What changes in the long-term care market?
12. What areas of the program do you think you might want to see changed in the future that we haven't yet discussed?

Wrap-up

13. Are there any written materials about or used in the program that we haven't yet seen that we should?
14. Is there anything I should have asked you that I didn't?

COUNTY COORDINATOR INTERVIEW

A. Sponsor Agency

1. What kind of agency is the sponsor agency? [If a home care agency]: Is this a non-profit or proprietary agency?

B. County Coordinator: To help us understand your perspective

1. How long have you been the county coordinator?
2. Before being county coordinator, had you worked in the administration or implementation of other government programs?
3. Had you been involved with long-term care before?
4. Are you a nurse? Social worker? Other profession? Do you work in any other capacity besides being the County Coordinator? If yes, in what way?

C. I'm going to ask you some questions about the SRCP's mission.

1. What do you perceive to be the goals or mission of the program? [If states more than one goal]: Which goal is most important? Who is the client of the program? [If needs prompting: care recipient, caregiver, both, whole family?]
2. How does your understanding of the program's goals shape the way you do your work in this county?
3. Do you perceive the program's mission or philosophy as having changed at all over time? How are those changes manifested in the work?

D. I'm going to ask you some questions about the way the program works in this county.

1. Who does the clinical assessments — your agency or do you subcontract them? [If her agency]: Do you do them yourself? [If no or contracted out]: Who does them — a nurse? Social worker? Other? Are they done in the client's home? Who does the reassessments? Are they done by telephone?
2. How often do you define a specific service plan for a client and how often are services decided on an ad hoc basis? Under what conditions do you do each? How do you go about deciding on and creating a service plan? How are clients [caregivers and care recipients] involved in that process?
3. If somebody has a service plan, how hard is it for them to deviate from that? If clients are receiving services on a more ad hoc basis, how much are you involved in helping them to decide on their services? Do you see yourself as playing a case management role with clients?
4. Do you have a way of managing how many services your clients are using? Do you schedule the year out in advance? How do you do this?
5. Do you generally have clients spending to the cap? If not, why not? If you do, is this a challenge and how do you manage this?
6. What do you do with the money you get from cost-share?
7. Which services do you offer?
8. How do you choose your service vendors? How often? Is there much competition? Is there much turnover? How many different vendors are you using?
9. How do you maintain oversight over the vendors?
10. How do you generally get new clients?
11. What do you do to advertise the program? How does the amount and kind of outreach you do respond to availability of slots?
12. What do you do with the leftover money if a client leaves the program or dies mid year?
13. When do you take on more clients rather than putting them on the waiting list?
14. How often do you think you speak or email with the Trenton office besides the monthly reports? What kinds of issues or decisions prompt this contact?
15. How often do you think you speak or email with other county coordinators outside of the quarterly meetings and annual conference? What kinds of issues or decisions prompt this contact?

E. I'm going to ask you some more evaluative questions about the program.

Overall

1. How does being a ________ affect the way you implement the program?
2. What do you thinking is working well in the program? What are the advantages of the program as it is currently designed?
3. What do you think are the advantages of how you implement the program in your particular county?

4. What are the benefits of the program to caregivers and care recipients?
5. What are areas that need improvement? What are disadvantages of the program as it is currently designed?
6. What are the disadvantages of how you implement the program in your county?
7. What are external obstacles to the program and your work?
8. What are the benefits to your agency of being a sponsor agency?
9. What are the disadvantages for your agency of being a sponsor agency?

Clients and Services

10. Do you have a sense of when most clients come to the program, i.e. at what stage of dealing with the disease or disability? What do you base this impression on? What do you think the impact is for the clients and the program?
11. Do you have a sense of what types of services are working best for clients? What do you base this impression on? What services do you think that clients need that they are not currently receiving?

Relationships/Operations

12. How many people work for SRCP and in what capacity do they do so? Is it paid or unpaid help? (Do you think you need more help?)
13. What are your impressions of program-client relationships, both for caregiver clients and care recipient clients? How well are they working? What are advantages and disadvantages of how the program is structured in this regard? Are you doing a client satisfaction survey? What does the survey tell you?
14. [If there are providers other than the sponsor agency]: What are your impressions of your relationships with the service providers? How well are they working? What are advantages and disadvantages of how the program is structured is this regard?
15. What is your impression of the service providers' relationships with the clients?
16. Do the service providers have any kind of routine check to make sure that their providers are doing a good job?
17. What is your impression of the relationship between the Trenton office and the county coordinators? How well is it working? What are advantages and disadvantages of how the program is structured is this regard?
18. Is the contact with other coordinators important to you in your work? Is there currently enough opportunity for that contact?

Changes

19. What do you think have been the most important changes in the program over time, either in the overall program design or in how your agency has done things? [Ask to describe and comment on implications of changes.]
20. What changes in the state and national policy context do you think have had an effect on the program? What changes in the long-term care market?
21. What areas of the program do you think you might want to see changed in the future that we haven't yet discussed?

APPENDIX II

TOPICS COVERED IN CLIENT SURVEYS (NINE COUNTIES REPRESENTED)

	ASPECTS ADDRESSED
AREA EVALUATED **Service Provider Staff**	Politeness, level of compassion, ability to establish rapport, time before a concern was addressed, ability to ensure comfort to the care recipient, promptness and completeness of service provision, advanced notice provided in the event of a cancellation of home care, appearance, trustworthiness, work performance, attitude, thorough supervision of the care recipient, knowledge and competence, overall satisfaction.
Service Provider Facilities and Administration	Cleanliness, safety and security, meal quality, timeliness and appropriateness of service, activities offered, professionalism, concern for service quality, adequate care recipient contact and supervision, assignment of consistent providers to promote continuity of care, convenience of location and time, equipment quality, rule enforcement, satisfaction with home care and in-facility services, willingness to refer friends/family members to the service provider, adequate communication between the provider and caregiver, adequate opportunities for family involvement in care recipients care, impact of in-facility services on the care recipient, overall satisfaction.
Sponsor Agency and Coordinator	Inclusion of clients in the service planning, thoroughness of home visits, knowledgeable and competent staff, communication between staff and medical professionals, advanced planning for future visits, satisfaction with the program coordinator, support staff, willingness to refer friends/family members to SRCP, availability of staff, advanced time warning for cessation of service provision, ability to get information relating to treatment, medications, and illness, facilitation of smooth and uncomplicated transitions, overall satisfaction.
Respite Program's Objectives	Did the caregiver get an adequate break? Did respite reduce the caregiver's stress level? Did the caregiver feel that the cost-share was affordable? Was respite helpful in preventing nursing home placement? What improvements are necessary? Could you remain in the community if the services you are receiving were not available? Did respite reduce the emotional and physical symptoms experienced during caregiving? Is the caregiver better able to cope and become more socially active after receiving respite? Has the ability to care for the care recipient improved after receiving respite?

ENDNOTES

[1] Lynn Friss Feinberg and Tammy L. Pilisuk, "Survey of Fifteen States' Caregiver Support Programs: Final Report," (San Francisco: Family Caregiver Alliance, October 1999).

[2] In the Statewide Respite Care Program, both caregivers and care recipients are considered to be clients. We therefore refer variously to clients in general, caregivers, and care recipients. Quotes from staff may sometimes use the word client to mean "care recipient."

[3] Although program data existed for 1992, the first year that the computerized system was employed, these contained very few of the variables of interest in the study, and were therefore removed from the analysis.

[4] Camperships provide caregivers with respite at the same time that they provide younger disabled with social and recreational opportunities. Institutional settings are generally perceived as less appropriate for the younger population.

[5] Currently the only hospital being used is a rehabilitation hospital, and the DHSS program office does not foresee use of acute care facilities.

[6] 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.

[7] That system was replaced by the FACTORS system in 2000.

[8] Program participants can petition to have their cost-share amounts changed. Given the fact that cost-share can be changed in this way, and as participant income is believed to generally remain stable over the period of participation, we have used the first recorded cost-share designation as the proxy for income. In some cases, participants have their cost-shares changed through petition even before their first program record, but this is uncommon.

[9] Because our records did not include program years prior to 1993 and because there is always the possibility of human error in data entry, we knew that we would not have acceptance/readmission records for some program participants. Service record codes of "active-services" or "active-no services" apply only to those who have been formally accepted into SRCP; therefore we used these as an indication of acceptance even when no acceptance or readmission record was available.

[10] Some counties also used the database to maintain records of clients whose applications for acceptance were pending. However, because counties were not required to do so, this information varies from county to county and has not been analyzed in this study.

[11] There are twenty-one coordinators serving the twenty-one counties. One coordinator serves two counties, and two coordinators serve one county. In the latter case, policies and practices involve both coordinators equally, so they will be considered as one coordinator (in one sponsor agency) throughout the discussion. The only exception will be when the discussion addresses the backgrounds of the individual coordinators, as their training and experience may differ. In short, we discuss twenty coordinators unless individual backgrounds of the coordinators are being discussed, in which case we discuss twenty-one coordinators.

[12] Later in the report we discuss whether differences in the actual use of aides can be seen by agency type.

[13] Later in the report we support this observation with county level service data.

[14] At a state level, money from the National Family Caregivers Support Program is not being distributed through SRCP because of incompatibility between the SRCP structure and the federal stipulation that NFCSP funds be administered through the Area Agencies on Aging. However, individual counties, if they choose to use these funds in part for respite care, will channel them through SRCP.

[15] 1990 US Census.

[16] The coordinators base their impressions of their care recipients' medical conditions at the time of entry on a number of sources including assessment forms, information provided by the family, interaction with the client, and the nature of the respite request (e.g., following recent hospitalization). One coordinator with a nursing background employs motor skill and dexterity tests to make a clinical judgement.

[17] Age distribution was quite similar for new admits and readmitted clients.

[18] This includes clients originally coded in the administrative data set as having either Alzheimer's disease/Senile Dementia or Organic Brian Syndrome, which is no longer recognized as a distinct diagnosis. This is (of necessity) a conservative estimate of the clients with AD/SD. For example, those with Parkinson's Disease were included in late-onset physical disability/disease, and those with "unspecified deterioration due to aging" were included in "other." Both diagnoses could indicate dementia.

[19] This distinction was not always easy to make, but the ambiguous cases would make only marginal differences to the percentages provided here. For example, a very small percentage of program participants had a diagnosis of blind, deaf, or unable to speak. Some of these may be lifelong disabilities, but — since we could not know which - all were grouped with late-onset physical disability.

[20] These estimates were based on data from the U.S. Census of 1990. The data available allowed us to classify the adult population as individuals 16 and above. We used the available income break of 1.9 percent of the poverty level, and included as disabled those who responded affirmatively when asked if they had a limitation in self-care. Elderly were defined as 65 and over, and the data allowed us to divide the population into those below and above the poverty level. This method of estimation provided a somewhat different allocation of low-income adult disabled by county than the estimation underlying the state's allocation of program dollars. However, it is close enough to allow for the comparison of program and population age and income distribution that follow.

[21] As the low-income adult disabled population was estimated based on 1990 data, we compared it to 1993 data for the SRCP. 1993 was the first year for which we had program data.

[22] All analyses of difference used a significance level of .05.

[23] The low-income adult disabled population was estimated with data which broke at 1.9% of FPL . Thus, if anything, our estimate of the percent of the low-income adult disabled population that was above poverty was high, strengthening this finding.

[24] It is possible that some of these 27 were also formal participants. However, there was nothing in the records available to us - either an admission/readmission record or an "active" record - indicating this.